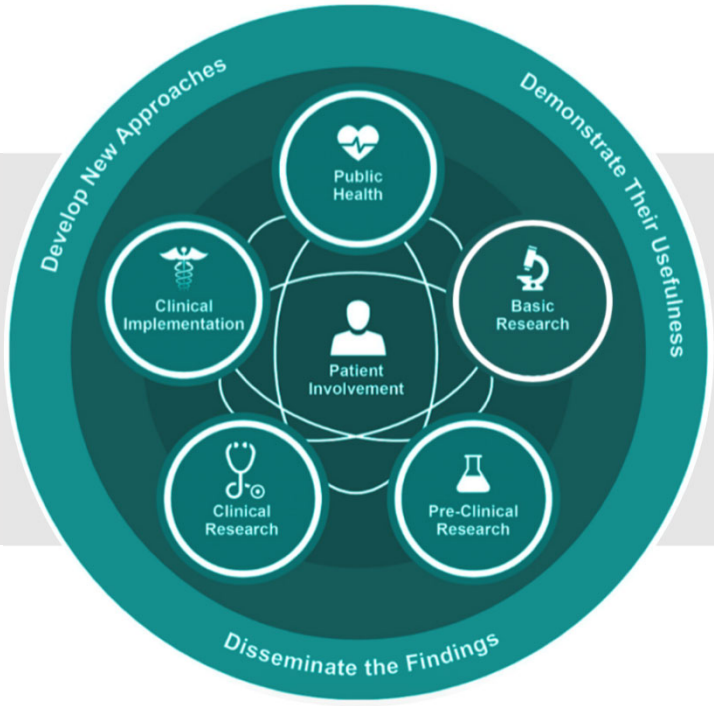

CTS Personas User Guidebook

CTS Personas is a collection of roles across the ecosystem of translational research.

Basic Research → Pre-Clinical Research → Clinical Research → Clinical Implementation → Public Health

These profiles are intended for use by the CTSA community and beyond, to assist anyone developing software projects, educational and communication materials, understanding stakeholder perspectives, and more.

This project is funded by the CTSA National Center for Data to Health (CD2H) and supported by the NIH National Center for Advancing Translational Sciences, Grant Number U24TR002306, to help guide the cultural and technological changes necessary for data and informatics to improve research and health care.

CTSA Clinical & Translational Science Awards Program

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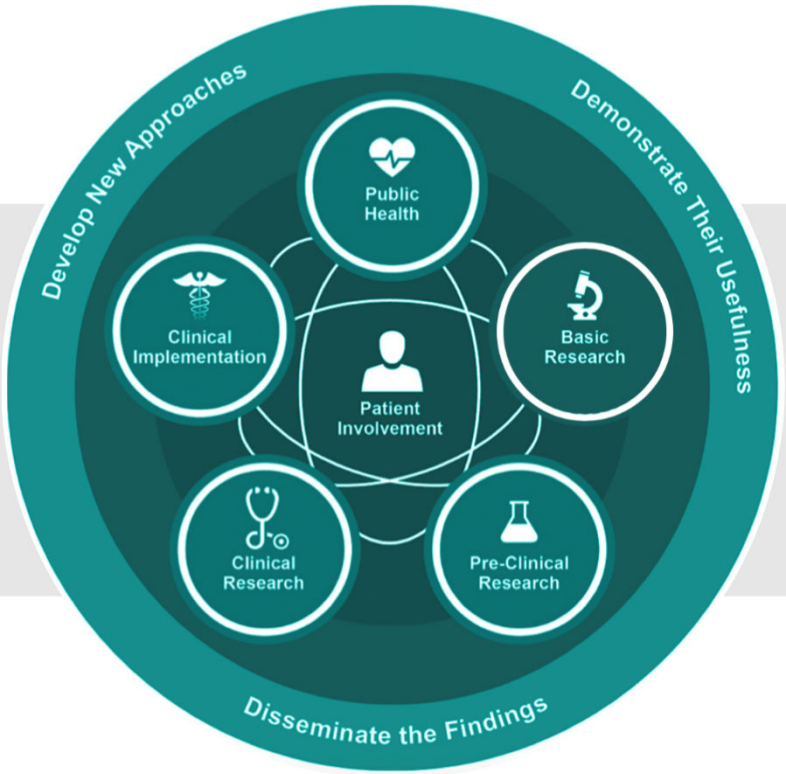
CTS Personas – The User Guidebook

CTS Personas, a project of the National Center for Data to Health (Grant U24TR002306), is an effort to create Persona profiles representing roles across the ecosystem of translational research.

Basic Research → Pre-Clinical Research → Clinical Research → Clinical Implementation → Public Health



In this guidebook you will find:

- *A key to the Persona profile layout*
- *A key to the Persona profile software icons*
- *A key to the Personas color codes for the translational ecosystem*
- *Sample Personas uses cases*
- *A comparison of common themes across the CTS workforce*
- *Acknowledgements*
- *Persona profile bibliographies*
- *Credits*

Persona Profile Key: *the translational workforce*

An effective Persona profile is one that not only outlines the work responsibilities and goals of a CTS employee, or the health conditions and healthcare needs of a patient, but also contains motivators, biographical information, a picture, and a name. Personal details remind the profiles' users that each profile represents a real person, with real concerns and challenges that they face every day in either their work or their patient experience in the CTSA network. Drawing profile elements from sources such as Usability.gov, the European Bioinformatics Institute, and UX magazine, and adding profile elements for scholarly outputs and continuing education needs (vital concerns for CTS employees), the following profile elements were created:

1. **Name**
2. **Photo**
3. **Quote**
4. **Descriptive Job Title**
5. **Major responsibilities**
6. **Expertise: training, years on job, etc.**
7. **Workplace environment**
8. **Software and data use at work**
9. **Technology attitude**
10. **Motivators**
11. **Goals**
12. **Wants/Needs**
13. **Pain points/Challenges**
14. **Scholarly output activities**
15. **Continuing Education Goals/Training Opportunities**

(4) Associate Professor of Biostatistics – Lindsay D'Amato (1)

(2) 

(3) "I enjoy multidisciplinary collaborative work and the opportunity to learn from a wide variety of scientists with different perspectives."

Bio (5)

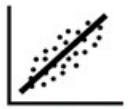
Lindsay's lifelong interest in improving people's health and happiness led her to the field of biostatistics for her PhD. Working her way up from a junior statistician position in which she cleaned datasets and performed simple analyses, she is now a direct collaborator with PIs on dozens of grant-funded projects each year. She advises researchers on the appropriate statistical approaches for analysis and plays a key role in study design. Many of Lindsay's projects are multi-center studies, requiring her to travel frequently. She provides mentorship to junior faculty in every stage of the research process, from study design to analysis. Lindsay also advises and mentors Master's level biostatisticians in her department, helping them along their path of professional development and promotion. Lindsay is grateful for the support of research administration staff and her colleagues in the grant office, who support her project work and assist her as she contributes to grant applications. One challenge Lindsay faces is the lack of an NIH study section to submit to for transdisciplinary grants. (14)

(6, 7)

Education: BS, Mathematics; MS, Statistics; PhD, Biostatistics
Years of experience: 10
Work location: Have laptop, will travel

Goals (11)

- To foster a biostatistics department for team science, to leverage complementary statistical expertise
- To establish clear communication with PIs about expectations
- To gain skills in new statistical programs and methods



(8, 9)

Software attitude & use

- Open to new tools
- When research and collaboration tools aren't working, she experiences delays
- Statistical software: SAS, Stata, PASS, R
- Research and collaboration: REDCap, Box, Trello, Github, Slack, video conferencing software
- Library Software: EndNote
- General: Microsoft Office Suite

Scholarly Outputs

- Articles/manuscripts
- Conference presentations & posters
- Class lectures, materials
- Reviews of others' manuscripts
- Grant application contributor

Pain Points (13)

- Harmonizing data from many different sources requires complicated behind-the-scenes biostatistics solutions
- Working on too many grants at low % effort leads to distraction, lower commitment, and less satisfaction

Motivators (10)

To receive funded grants, thereby confirming viable research analysis design

To get recognition for vital role biostatisticians play on statistical analyses in research

To report accurate and impactful results

To do accountable, reproducible science that ensures the safety and security of patient data

Wants/Needs (12)

- Formal recognition for collaboration, leadership, and mentorship on team projects
- More time to achieve her goals
- Institutional support for a biostatistics collaboration unit
- A way to track metrics on consulting and collaboration efforts to document productivity
- Clear methodology or algorithm for prioritizing requests

Professional Development (15)

Department supports travel to conferences, workshops, purchasing informational resources

Mentors Master's level biostatisticians

Department encourages biostatisticians to pursue their PhDs

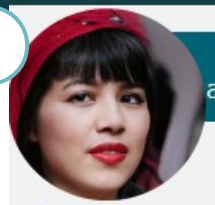
Wants to pursue a professional statistical certification (PStat) from the American Statistical Association

Persona Profile Key:
academic health center patients

Effective Persona profiles for patients, aside from providing insightful background and biographical information, provide insights into how the patient currently interacts or may wish to interact with the resources and services available to them at CTSA sites and beyond. The following profile elements were chosen for the insights they offer into healthcare beliefs, practices, and the opportunities for engagement that they elucidate between a health center and its patients:

1. **Name**
2. **Photo**
3. **Quote**
4. **Biographical sketch**
5. **Education level**
6. **Employment status**
7. **Work location(s)**
8. **Health conditions**
9. **Healthcare influences**
10. **Goals**
11. **Software attitude and use (with an emphasis on how software is used to manage healthcare)**
12. **Wants/Needs**
13. **Support network**
14. **Opportunities for a CTSA or other health provider to connect with the patient through a website or online tool**

Patient – Emily Trinidad (1)


(2)

"I want a way to quickly and authentically connect with mental health providers and peers who face the same issues, to reduce my anxiety about the future." (3)

Bio (4)

Emily is the eldest of four children. Emily's parents, immigrants, both work and stress the importance of education. She was an overachiever in high school and the first in her family to attend university. She feels pressure to make her parents proud and to set a good example for her younger siblings. She chose not to stay on campus, living with her family to save money and to help her family. She feels stressed about safety on campus and in the city. She feels a lot of stress about world events but powerless to change things. She worries about money. School, work, and home responsibilities leave little time for fun and Emily often feels lonely or cut off from friends.

Emily works very hard to manage her time so that she can get good grades. She works 20 hours a week and considers this the only time she has to hang out with friends. She does not sleep as much as she needs or would like. Until she sought help for her depression and anxiety, she only saw medical professionals for check-ups or when she was sick. She now makes time to see her therapist on campus every other week.

(5)

Education: BSB, Business (pending, sophomore); considering change to art
Years of experience: 1
Work location: Moves between school and work as a barista

(6,7)

Health Conditions (8)

- Generally in good health, and ha… recently been diagnosed with anxiety and depression
- Covered on mother's health insurance
- Emily finds her own providers, makes her own appointments

Healthcare influences (9)

- Emily had regular childhood me… check-ups. Her mother managed her healthcare and her father approved mother's decisions
- Initially diminished her depression symptoms because her family does not believe in mental health issues as an illness
- The ease with which Emily's friends share their mental health experiences and struggles have normalized therapy for her

Goals (10)

- Emily wants to manage her s… and anxiety so she can be productive at school, work, and life
- Emily wants to obtain virtual access to healthcare providers
- Emily wants online scheduling and ability to text questions to her provider

Software attitude & use (11)

- At ease with technology but prefers face to face interactions, to make what she considers to be more authentic connections
- Uses a smartphone, laptop to manage her healthcare
- Social media: YouTube, Instagram, Snapchat. Like many in Gen Z, she strongly prefers visual content over written content
- General: MS Office & Google Suites

Opportunities to connect (14)

Apps are important to reach… Emily

Integrate existing tools, like Instagram, into websites for patients like Emily, to share authoritative yet personal and engaging information

Provide easier and more flexible scheduling tools. Emily wants to see last minute cancellations and book 'on the fly'

Wants/Needs (12)

- Health care providers who do n… down to her due to her age or gender
- Health care providers who listen, care, and are readily available to help
- More help evaluating medical information for authority, accuracy, and bias. She feels she reads enough for school and doesn't have the time to do it for her healthcare, too
- To watch video content about tools to cope with depression and anxiety
- Rapid, personal connections with doctors via social media, FaceTime
- Flexible, night/weekend appointments

Support Network (13)

Emily's mother and friends are her … supporters. She says there were perio… her freshman year when 'she could have used more support'

Friends support Emily at her workplace as well as through texts, SnapChat or Instagram during the day

Would like to use mobile medication or therapy apps, but can't afford the fees

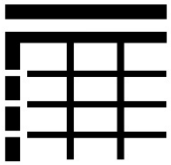
Emily needs additional support. She wants tools to connect her with other college students who deal with anxiety and depression

Persona Profile Key: Software Use Icons

Each Persona created through the CTS Personas project is based on research on real professionals in the field, all of whom utilize many different software types through many devices in the course of their work. To help profile users associate a Persona with the type of software programs that they utilize most, each Persona was assigned an icon. A key to the icons can be found below:

Desktop Researcher

The desktop researcher's primary software-based activities include Internet searching for scholarly publications and data, and writing and reviewing manuscripts in the case of a CTS employee. A patient desktop researcher uses the Internet to research healthcare topics and providers and to schedule appointments. Both the patient and employee use the Internet on a computer for communication and social media. General office suites such as Microsoft and Google are commonly used.

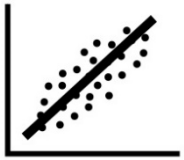


Spreadsheets

A skilled spreadsheet user uses programs like Excel to collect data (both patient-related and financial), manipulate and analyze data, and to perform calculations and basic visualizations.

Visualization

Employees with visualization skills employ a variety of programs to visualize data for the purposes of teaching, presentations, and research impact and promotional reports. Programs commonly used for these purposes include: OpenRefine, Python, R, R Studio, Tableau, VOSViewer, and Jupyter Notebooks.

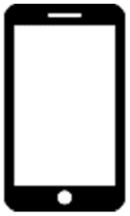


Statistical Modeling

Employees with statistical modeling skills use a variety of software programs to analyze and visualize data. Some use statistical programs in study design and throughout the process of a research project or clinical trial. Commonly used programs include: SAS, Stata, SPSS, and R.

Scripts & Coding

Employees with skills in scripts and coding use various programming languages to write complex database queries and to develop software solutions for both employee and patient end users in the CTSAs. Commonly used programs include: SQL, Ruby, Python, Java, JavaScript, DataGrip, RubyMine, Jenkins, and Postgres



Mobile

A mobile user may use computers in certain settings, but a mobile phone or tablet is often the first medium through which they will interact with many online resources including hospital and provider portals, appointment scheduling software, online consultations with doctors, websites for research, and texting, email, and social media for both professional and personal communication.

Persona Profile Key: Color Key to the Translational Ecosystem

Each Persona profile contains a band of color in the upper right corner to demonstrate where the role lies within the translational ecosystem. Following the NIH's outline of the CTS ecosystem, colors have been matched to categories of roles as follows:

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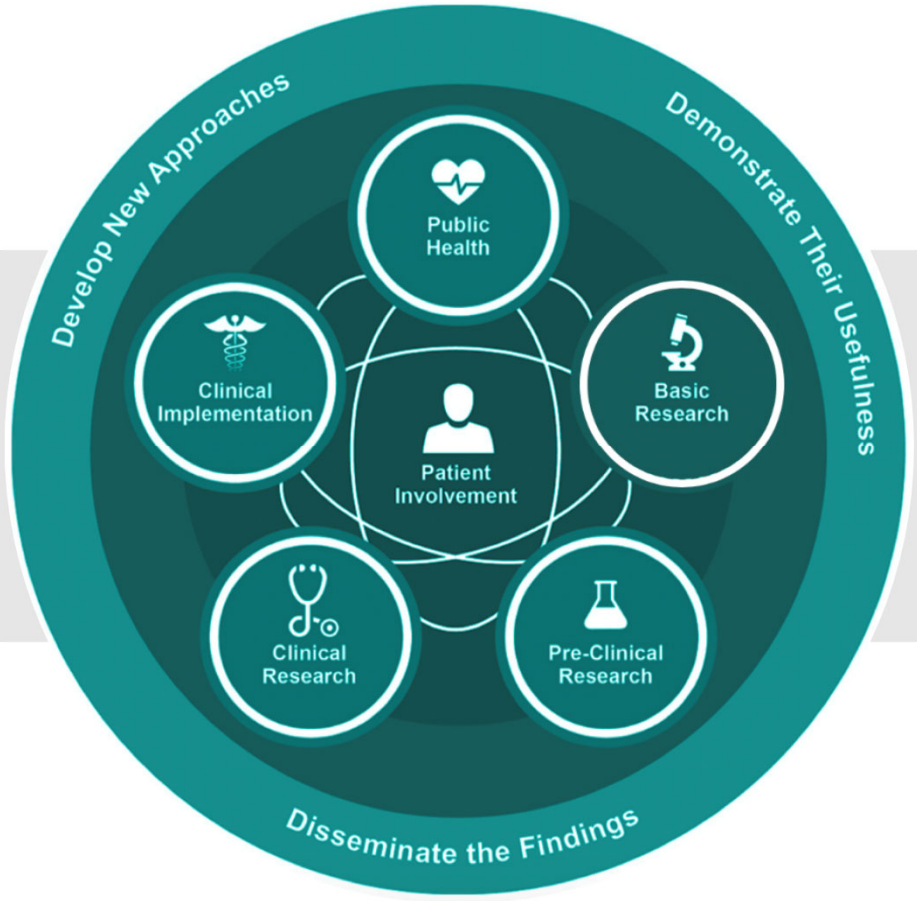
Sample Personas Use Cases

In the following pages you will find sample use cases outlining how the Personas can be used to illustrate and support software, educational, and communications projects at your institution.

New use cases are welcome! Contribute your use case at: https://github.com/data2health/CTS-Personas/issues



Use Case 1: End to End Patient Platform

Greta
Community-Engaged Researcher

Eli
Developer

Greta received a grant to create an end-to-end patient portal. She is gathering requirements and thinking about design aspects to share with Eli, who will create the portal.

End-to-End Patient Portal

Platform functions:

- Schedule appointments
- Securely manage patient data
- Interact with providers

Allows patients & caregivers to:

- Access cancer (or other serious health issue) information
- Communicate more easily with physicians
- Participate in clinical trial matching programs
- Find social support
- Find resources more easily with the help of their lay patient navigators, and vice versa

Who uses the portal? Who benefits?

Tom
Patient

Alice
Patient Navigator

Carmen
Center Administrator

Lindsay
Biostatistician

Simran
Physician Scientist

Melody
K Scholar

Greta and Eli found the Personas invaluable for building their user/stakeholder information:
Tom, a patient in his eighties, and **Alice**, a busy Patient Navigator, are considered primary users. Portal interface design is influenced by their needs, including Tom's need for larger print, and Alice's need for fast access to resources given her busy caseload. In addition **Alice**, Center Administrator **Carmen**, and Biostatistician **Lindsay** want to gather de-identified data from the tool to better understand the patient journey through statistical analysis. Eli builds out a data exporter function to serve their needs. Researchers **Simran** and **Melody** are able to benefit from both the raw data and others' analyses by using them as foundational research for their projects, and this evidence-based research will help their work to have a direct impact on patient outcomes.

Use Case 2: Clinical Research Center Trainings

Carmen
Center Administrator

Clinical Research Center Administrator Carmen is working on the Center's trainings schedule for 2020. Clinical Research Coordinators and Research Administrators have been her primary audience, but she would like the trainings to serve more stakeholders at her CTSA.

Learning about the time constraints on most of these Personas from their profiles leads Carmen to branch into new class offerings, such as asynchronous and web-based learning.

Consulting the Persona profiles helps Carmen consider the following audiences and their needs:

- **Irene** (Research Administrator): needs classes in latest updates to pre-award rules and regulations, compliance, and mathematical and statistical courses
- **Lucy** (Clinical Research Coordinator): needs classes in Good Clinical Practices, stress management, Python and R for data management
- **Melody** (Researcher): needs classes in Good Clinical Practices and study design
- **Lindsay** (Biostatistician): understands statistical aspects of study design, but wants to take a clinical study design class to see how her work can meld with it more smoothly. A Good Clinical Practices class would also help her in that regard.
- **Simran and Greta** (Clinical Researchers): Given their time commitments and constraints, the researchers would like quick refreshers on study design. They also want trainings for themselves and their teams on all the resources that the Center offers for clinical research, so team members know where to turn for help with specific problems.
- **Rachael** (Librarian) and **Jim** (Data Analyst): want classes in Good Clinical Practices to help them better serve their clients, the majority of whom are clinical researchers.

Trainings Audiences

Lucy
Clinical Research Coordinator

Irene
Research Administrator

Lindsay
Biostatistician

Melody
Researcher

Simran
Physician Scientist

Greta
Community-Engaged Researcher

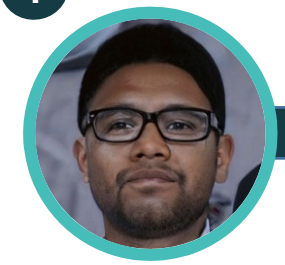
Rachael
Librarian

Jim
Data Analyst

Use Case 3: Building the Software Development Team

Attracting the best candidates:

1



Clinical Research Center Software Development Team recruitment

Eli
Developer

The head of digital systems at a Clinical Research Center is trying to build her software development team and is having a hard time hiring. After a couple failed attempts, she decides to work with the CTSA's talent partner and access the user persona for the developer role (Eli Daniels) to see what they are missing. They are able to learn more about developer motivations, such as the importance of the team being able to create open source tools to share with other hubs. They also learn that the team feels under-supported in terms of project management and UX expertise. The head of digital systems works with her talent partner to re-write the job posting to highlight the commitment to open source technologies and communicate the scope of the work being done. In interviews the talent partner and head of digital systems refer to the motivators and goals of this persona to effectively communicate and "sell" the role to top candidates.

Other staffing & resource stakeholders:

2

Understanding resources and building capacity

Carmen
Center Administrator

The head of digital systems and the talent partner are sympathetic to developers' needs for support staff, but anticipate that their Center Administrator may lack the funds to budget for them. They consult Carmen's profile to learn about her motivators and goals, and keep these in mind before scheduling a conversation on this topic with their own Center Administrator. After engaging in a balanced dialogue, and learning from Eli's profile information and the candidates' requests, their local administrator shifts her fundraising focus to include more funds for development support staff.

3

Lindsay
Biostatistician

Jim
Data Analyst

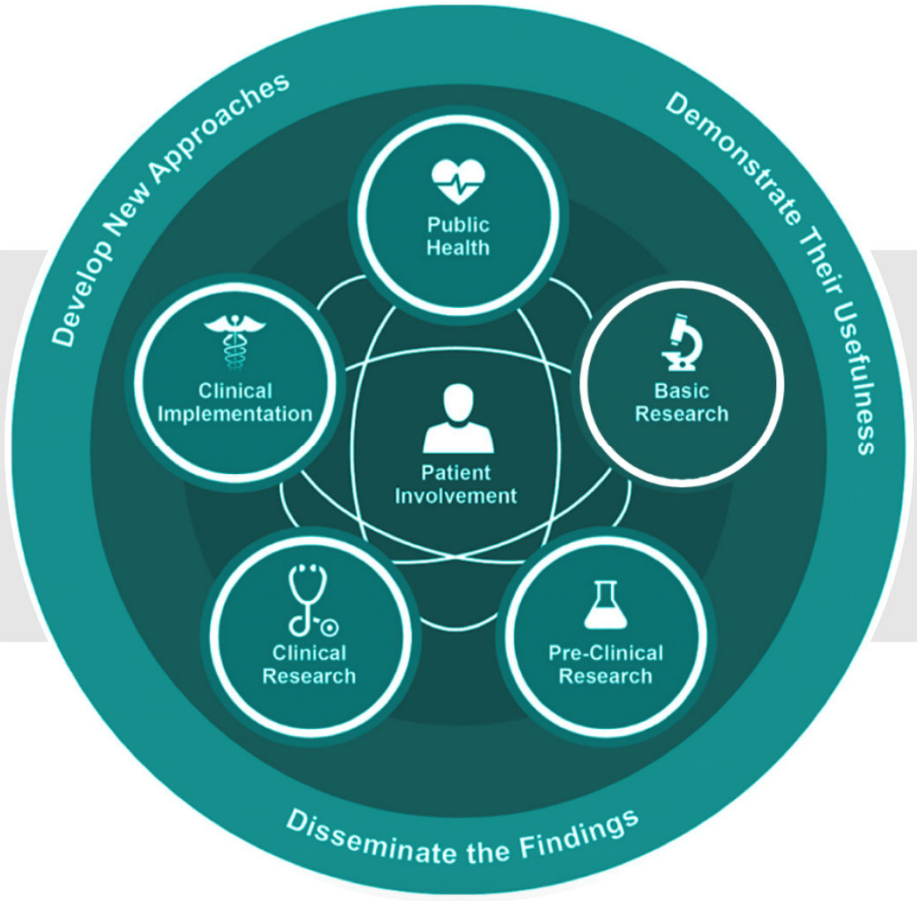
Strategic approach for future team development

The talent partner takes what she has learned from her experience with digital systems and performs a similar scan for support needs, using Personas, in the biostatistics and data analysis departments. She confers with their heads on strategies to hire more support staff in their areas.

CTS Employees: Behind the Profiles

The following pages contain visualizations of some of the common themes and concerns that arose between and among the CTS roles, as elucidated through research and interviews.

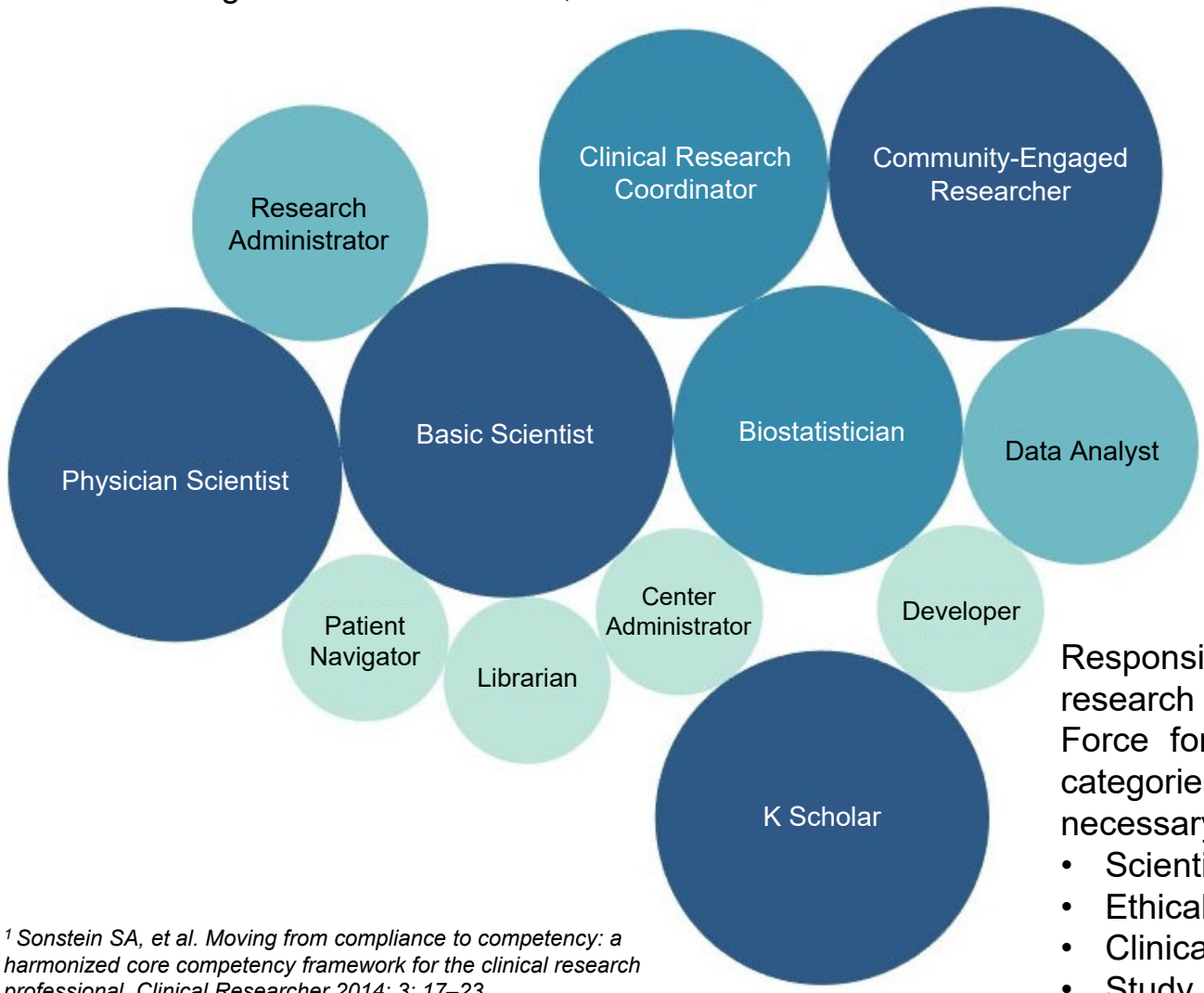
For detailed information about software programs used by each of the Personas, see the CTS-Personas GitHub page at: https://data2health.github.io/CTS-Personas/



Conducting Reproducible Research

Reproducible research in basic science and clinical trials is the work at the heart of the translational ecosystem. To conduct reproducible research, investigators must be mindful of ethical concerns, patient data safety, study design, statistical analysis, and documentation.

However, not only PIs are concerned with conducting ethical, reproducible research. All the Personas profiled have an interest in it, and some have direct involvement in its conduct. The bubbles below are sized from smallest to largest based on a light-to-dark color scale, as defined below.



Key

- *Supports reproducible research in a secondary way*
- *Directly supports reproducible research*
- *Helps conduct reproducible research*
- *Responsible for reproducible research projects*

Responsibilities of conducting reproducible research demonstrate the following Joint Task Force for Clinical Trial Competency Domains[1-2], categories of knowledge, skills, and attitudes necessary for clinical research.

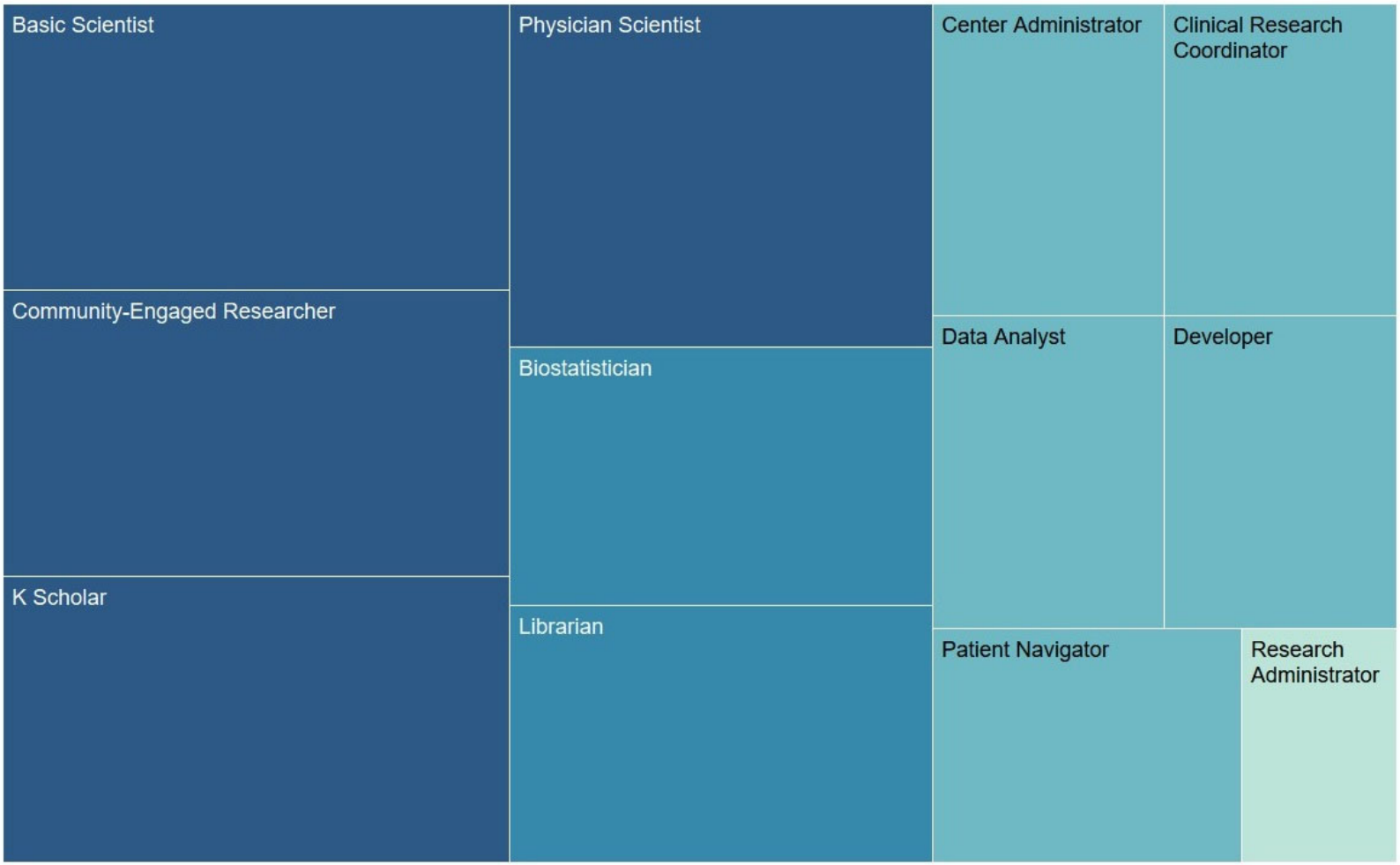
- Scientific concepts and research design
- Ethical and participant safety considerations
- Clinical trials operations/good clinical practices
- Study and site management

[1] *Sonstein SA, et al. Moving from compliance to competency: a harmonized core competency framework for the clinical research professional. Clinical Researcher 2014; 3: 17–23.*

[2] *https://clic-ctsa.org/education/competencies*

Producing Research Outputs

Traditional research outputs such as peer-reviewed publications and conference presentations are the coin of the realm in biomedical research. Investigators have traditionally been most concerned with increasing their publications, but increasingly many of the employees who support translational science are producing such outputs. In addition, they desire attribution for their contribution to studies, and they wish to track their impact through both traditional research metrics and newer avenues such as social media mentions. The boxes below are sized from smallest to largest in terms of frequency of research output production for each of the Personas on a light-to-dark color scale, with darker shades denoting most frequent production.



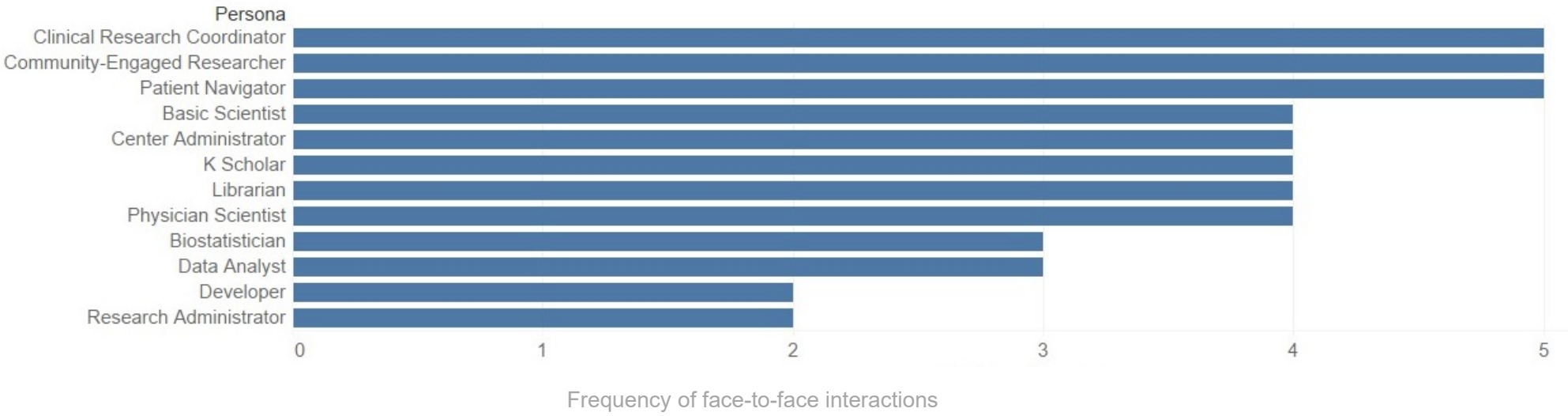
Key

- *Not applicable*
- *Does not frequently produce traditional outputs, but would like attribution when they do*
- *Occasionally produces outputs; would like to produce more*
- *High pressure to produce outputs; attribution and metrics are vital to future promotion and funding*

Working both Mobile and Face-to-Face

Powerful laptops and VPN access to files allow many members of the translational workforce to work from home. However, for many, face-to-face interactions are vital. Face-to-face interaction fosters improved communication and greater understanding of workflows and goals, which is essential for ethical, reproducible, team science. The graph below demonstrates each Persona's frequency of face-to-face work, even when mobile options are available.

Preference for Mobile vs. Face-to-Face Work



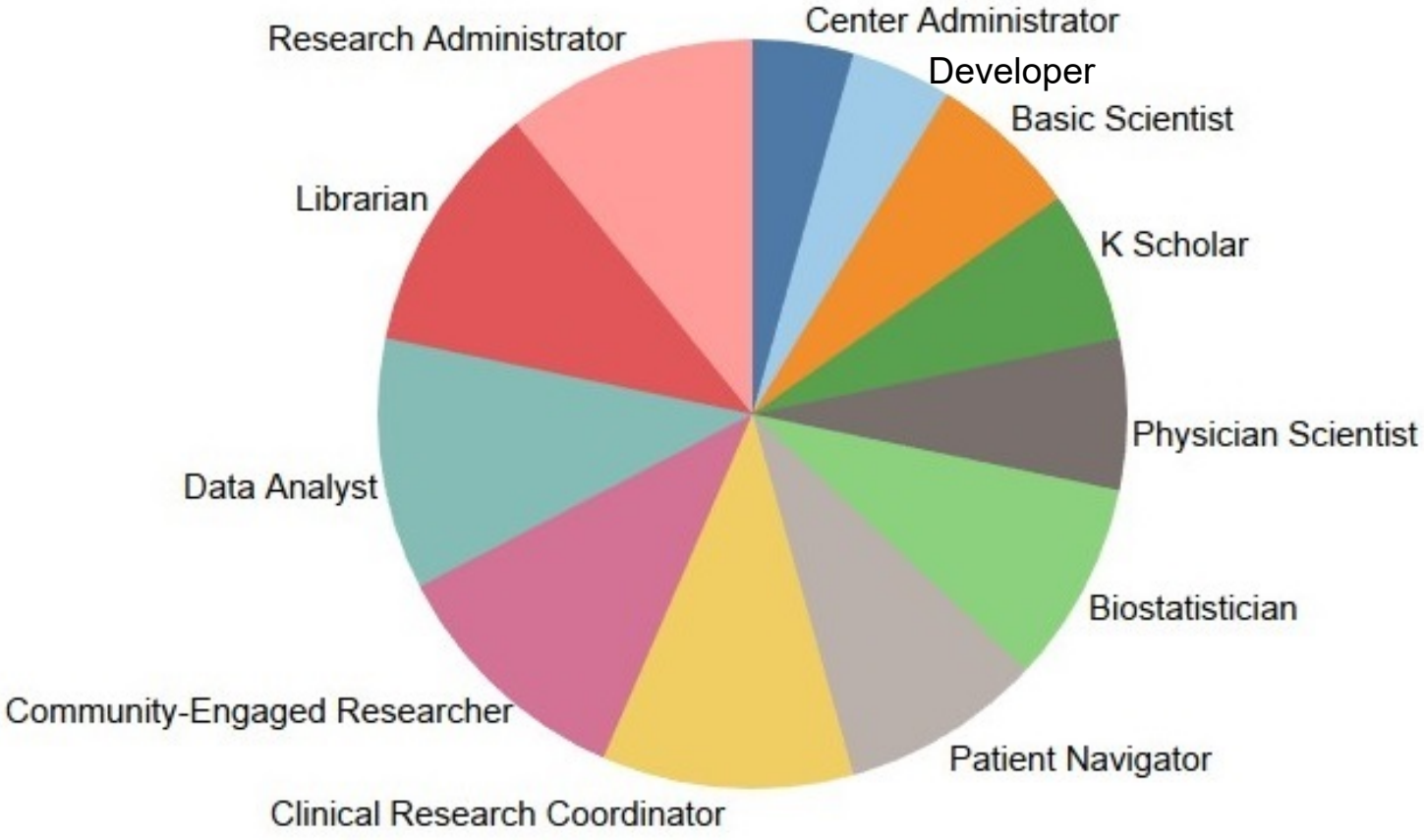
Commitment to face-to-face engagement in the era of mobile work demonstrates the following Joint Task Force for Clinical Trial Competency Domains[1-2], categories of knowledge, skills, and attitudes necessary for clinical research.

- Leadership and professionalism
- Communication and teamwork

[1] *Sonstein SA, et al. Moving from compliance to competency: a harmonized core competency framework for the clinical research professional. Clinical Researcher 2014; 3: 17–23.*
[2] *https://clic-ctsa.org/education/competencies*

Interoperability Between Data Sources

Whether harmonizing and reconciling biomedical datasets from disparate sources, or gathering information from multiple online platforms to complete grant contracts and budgets, employees across the CTS landscape face the challenges of compiling and analyzing data between systems. Occasionally the systems in question cannot “talk” to each other due to security concerns; in other cases, legacy data repositories are involved. Below is a chart demonstrating the extent to which interoperability between systems, or an easier way to map data from different systems, was expressed as a desire in the Personas research. The size of the pie slice corresponds to the need for interoperability.



A commitment to solving interoperability problems demonstrates the following Joint Task Force for Clinical Trial Competency Domains[1-2], categories of knowledge, skills, and attitudes necessary for clinical research.

- Data management and informatics

[1] *Sonstein SA, et al. Moving from compliance to competency: a harmonized core competency framework for the clinical research professional. Clinical Researcher 2014; 3: 17–23.*
[2] *https://clic-ctsa.org/education/competencies*

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Oregon Health & Science University:
Robin Champieux

Washington University:
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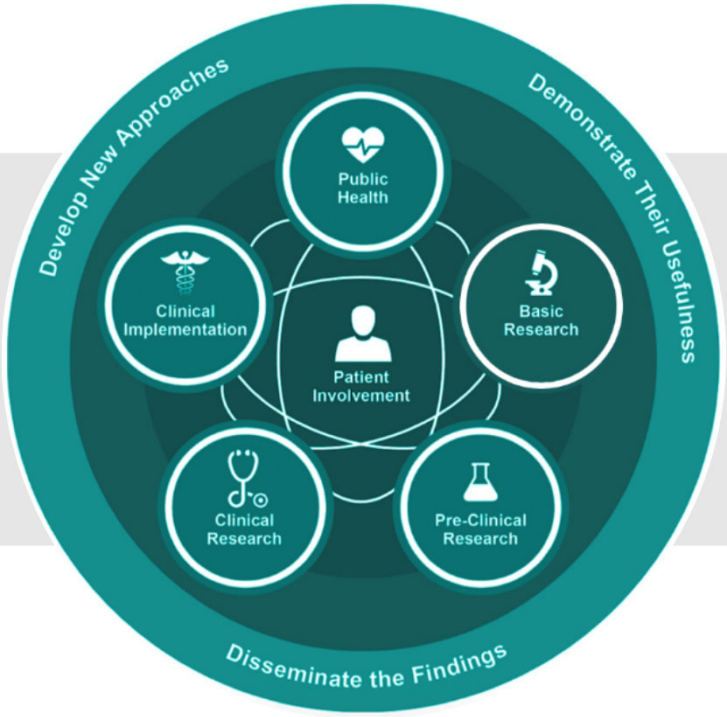

Special thanks especially to those employed in the clinical and translational sciences who allowed the project team to interview them to inform the profiles. Your help is much appreciated!

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Biostatistician (Associate Professor of Biostatistics – Lindsay D'Amato)

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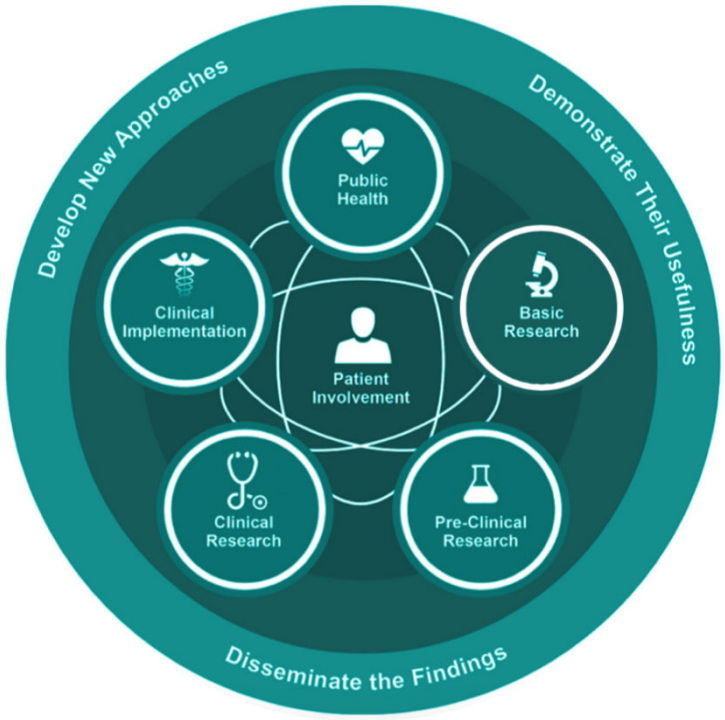

- Applied Data Science for Research graphic is the source of all the Software Use icons. All icon images are copyright Jonah M. Duckles – 2019, licensed as CC-BY. Available at https://github.com/jduckles/dsskills.
- Melissa Buote (melissabee.ca) is the designer of the Personas Trading Cards.
- This Person Does Not Exist is the source of all Personas images. The creators of this website used AI to generate realistic human faces that are not based on any real person. Available at https://thispersondoesnotexist.com
- Translational Science Spectrum image is from the NCATS Strategic Plan, available at https://ncats.nih.gov/strategicplan/introduction

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