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.

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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.

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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
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
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

**Health Conditions**
- Generally in good health, and has recently been diagnosed with anxiety and depression.
- Covered under a family plan.
- Emily manages her own health and makes her own appointments.

**Healthcare influences**
- Emily had regular childhood medical check-ups. Her medical manager worked as her personal health care provider.
- Initially diminished her depression symptoms because her family believes treatment is effective. Her friends share their mental health experiences and struggles have normalized her behavior.

**Goals**
- Emily wants to continue managing her health by communicating with her health care provider and taking her medication as prescribed.
- Emily wants to connect with a mental health professional for support.
- Emily wants to connect with a health care provider for support.
- Emily wants to connect with a health care provider for support.

**Software attitude & use**
- At ease with technology, but prefers face to face interactions, to make what she considers to be more authentic connections.
- Uses a smartphone, laptop, and computer to manage her healthcare.
- Social media: YouTube, Instagram, Snapchat. Emily also enjoys playing video games and watching TV.
- Emily prefers written content over visual content.

**Support Network**
- Emily's mother and friends are her primary support system. They always make time for her and help her through tough times.
- Emily's workplace provides her with a support group and resources to deal with stress.
- Friends provide emotional support and are always there for her.

**Opportunities to connect**
- Emily's workplace provides her with a support group and resources to deal with stress.
- Friends provide emotional support and are always there for her.
- Emily's workplace provides her with a support group and resources to deal with stress.
- Friends provide emotional support and are always there for her.
- Emily's workplace provides her with a support group and resources to deal with stress.

**Wants/Needs**
- Emily wants to connect with a mental health professional for support.
- Emily wants to connect with a health care provider for support.
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- Emily wants to connect with a health care provider for support.
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 CTSA. 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.

All icon images are copyright Jonah M. Duckles - 2019 Licensed as CC-BY, except the phone image, which is copyright: https://svgsilh.com/svg/1976104.svg
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:

- **Purple**: Basic Research
- **Blue**: Pre-Clinical Research
- **Light Green**: Clinical Research
- **Yellow**: Clinical Implementation
- **Red**: Public Health
- **White**: Role Spans the Translational Workforce
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 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

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.
Use Case 3: Building the Software Development Team

### Attracting the best candidates:

1. **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. **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. **Jim**  
   Data Analyst  
   **Lindsay**  
   Biostatistician

   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.
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.

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

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\(^2\) 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.

<table>
<thead>
<tr>
<th>Basic Scientist</th>
<th>Physician Scientist</th>
<th>Center Administrator</th>
<th>Clinical Research Coordinator</th>
</tr>
</thead>
<tbody>
<tr>
<td>Community-Engaged Researcher</td>
<td>Biostatistician</td>
<td>Data Analyst</td>
<td>Developer</td>
</tr>
<tr>
<td>K Scholar</td>
<td>Librarian</td>
<td>Patient Navigator</td>
<td>Research Administrator</td>
</tr>
</tbody>
</table>

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\textsuperscript{1-2}, categories of knowledge, skills, and attitudes necessary for clinical research.

- Leadership and professionalism
- Communication and teamwork

\textsuperscript{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

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\(^2\) https://clic-ctsa.org/education/competencies
The CTS Personas project could not have been completed without the collaboration of the project partners:

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**Persona Profile Bibliographies**

**Basic Scientist (Professor of Developmental Biology – Arthur “Art” Rosen)**


**Biostatistician (Associate Professor of Biostatistics – Lindsay D’Amato)**


Clinical Research Center Administrator (Carmen Lukovich)


University of Illinois at Chicago, Center for Clinical and Translational Science, Services & Facilities. https://www.ccts.uic.edu/content/clinical-research-services-facilities
Clinical Research Coordinator (Lucy Silonga)


Persona Profile Bibliographies

Community-Engaged Researcher (MD, PhD in Epidemiology – Greta Oftedal)


**Data Analyst (Jim Blair)**


Research Data Analyst Associate. Job Posting. Northwestern University CTSI. [https://www.indeed.com/rc/clk?jk=f531a5e6132400e5&fccid=bc51f56762438d6f&vjs=3](https://www.indeed.com/rc/clk?jk=f531a5e6132400e5&fccid=bc51f56762438d6f&vjs=3)


**Developer (Eli Daniels)**


Software Developer Job Posting. Northwestern University


KL2 Scholar (Assistant Professor of Pulmonology – Melody Zainal)


Assistant Professor in the Clinical and Translational Science Center. Job Posting. University of New Mexico. https://www.higheredjobs.com/search/details.cfm?JobCode=176834240&Title=Assistant%20Professor%20of%20CTSC%20%28req6603%29


Librarian (Research Impact and Bioinformatics Librarian, Rachael Pereira)


Persona Profile Bibliographies

**Patient Navigator (Alice Hougen)**


Patient Navigator Barrier and Outcome Tool (PN-BOT). George Washington School of Medicine and Health Sciences. 2016 [Accessed 9 July 2019](https://smhs.gwu.edu/gwci/BarriersTool)
Persona Profile Bibliographies

**Patient Navigator (Alice Hougen, continued)**


Physician Scientist (Professor of Medicine in Gastroenterology – Simran Gupta)


### Patient 1 (Emily Trinidad)


LatinX. Anxiety and Depression Association of America. [https://adaa.org/hispanic-latinos](https://adaa.org/hispanic-latinos)


### Patient 2 (Thomas “Tom” Movell)


Medlock, Stephanie et al. “Health information-seeking behavior of seniors who use the Internet: a survey.” *Journal of medical Internet research* vol. 17, 1 e10. 8 Jan. 2015, doi:10.2196/jmir.3749

Turner, Anne M et al. “A Closer Look at Health Information Seeking by Older Adults and Involved Family and Friends: Design Considerations for Health Information Technologies.” *AMIA ... Annual Symposium proceedings. AMIA Symposium* vol. 2018 1036-1045. 5 Dec. 2018


CTS Personas - Credits

- 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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