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putting the pieces together: theory and practice

Using Data Interviews to Map Research Data Services (RDS) Needs at a Health Science Institution

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Abstract

Objective: On January 21, 2023 the National Institutes of Health Data Management and Sharing Policy (NIH DMSP 2023) went into effect. Ahead of these expanded data sharing requirements, the Health Sciences Library at the University of Tennessee Health Science Center (UTHSC) set out to better understand health science research data service (RDS) needs and how the Library could develop new services in alignment with existing institutional support.

Methods: Building upon a set of data interview questions created by Read et al. (2015), the author conducted a series of semi-structured interviews with 10 researchers in the fall of 2022. The interview transcripts were inductively coded and analyzed for themes relevant to RDS needs.

Results: Analysis of the interviews identified several opportunities for the Library to take ownership of RDS activities in the areas of support services, training and instruction, and tools and technology. Additionally, these interviews helped to characterize existing institutional support and to develop an informal community of practice at the University of Tennessee Health Science Center (UTHSC). These RDS topics were mapped onto Harvard's Biomedical Data Lifecyle to further clarify areas of need and opportunities for growth for the Library and institutional RDS partners.

Conclusions: The study identified critical RDS needs among UTHSC researchers and highlighted the potential role of the Library as a valuable partner in addressing these needs and fostering collaboration among campus stakeholders. Conversations informed by these findings continue with stakeholders about the best way to meet the needs of researchers on campus as well as centralize and coordinate existing endeavors.

Introduction

The need for research data management (RDM) and, more broadly, research data services (RDS) support has increased steadily over the last 20 years in response to growing commitments to open science and data reuse by global funding agencies. Most recently, the National Institutes of Health (NIH) began requiring the submission of and adherence to a data management plan (DMP) for all federally funded research producing scientific data under the 2023 NIH Data Management and Sharing Policy (DMSP) (National Institutes of Health 2023). On the heels of the NIH DMSP, The Office of Science and Technology Policy (OSTP) released an open access memo in August 2022 providing policy guidance to federal agencies for "ensuring free, immediate, and equitable access to federally funded research (Executive Office of the President, Office of Science and Technology Policy 2022)."

Growing momentum for open science in the United States has motivated many academic institutions to take stock of the emerging needs of their researchers and the capacity of existing support units to meet new and increased demand for research data services (RDS). The academic library has a long history as a research support hub on university campuses and librarians are well-suited to hone and deploy their skills as leaders for RDS-related tasks (Rice and Southall 2016; Koltay 2019). Library RDS often aim to "provide information, consulting, training, or active involvement in: data management planning, data management guidance during research (e.g. advice on data storage or file security), research documentation and metadata, [and] research data sharing and curation (selection, preservation, archiving, citation) (Fearon et al. 2013)." The management and sharing activities required for funder compliance are well suited to librarian expertise. RDS activities are established in the literature and in practice, making them a logical entry point for libraries looking to become more involved in research support at their institutions. In addition to the work and expertise of academic libraries, the complex nature of research data services often requires that efforts are coordinated amongst many institutional units, such as information technology, research offices, statistical support groups, internal review boards (IRB), data intensive researchers and labs, and university counsel (Smith et al. 2022). As such, the establishment or enhancement of RDS could be best approached as a collaborative effort amongst existing campus stakeholders.

Background

The University of Tennessee Health Science Center is a statewide, public, R1, academic health system with over $132 million in grant and contract awards in FY2022. The NIH is the largest funder by dollars awarded to UTHSC researchers. In spring 2022, less than a year before the January 2023 launch of the NIH Data Management and Sharing Policy (DMSP), UTHSC Health Sciences Library faculty began fielding reference questions and support requests for the upcoming policy changes. In response, the author began reviewing previous work assessing Library stakeholders' research data management (RDM) needs, beginning with an initial scan of campus RDM activities conducted in 2017. The 2017 report found that University data management and organization practices were primarily concerned with institutional data, rather than

scientific research data. Given the evident gap in research data management support on campus, the Library began building internal RDS capacity by hiring two new full-time faculty positions in 2018 and 2022.

When assessing the need for and suitability of new services, libraries may direct their focus externally, such as with an online audit or survey of offerings at peer institutions, or internally, at the needs of their own users (Soehner, Steeves, and Ward 2010). Frequently a combination of these approaches is utilized. The internal assessment methods used to guide the development of new data related services commonly include discussions with focus groups or interviews with researchers and other stakeholders (Westra 2010; Read et al. 2015). At UTHSC, growing campus interest in how the Library could support NIH-funded researchers motivated a second environmental scan to update the 2017 findings, predominantly informed by a series of data interviews with researchers in fall 2022. These interviews were intended to evaluate the "data-related challenges and needs of an institution's researchers," often with regards to data management specifically (Read et al. 2015). The goal of these interviews was to better understand the existing institutional RDS environment, including infrastructure and personnel, as well as individual researcher perspectives and needs around data management and sharing. Importantly, findings on researcher needs were understood to be fluid and subject to change as the landscape of scientific research data management and sharing continues to evolve (Westra 2010).

Methodology

The author conducted semi-structured, in-depth interviews adapted from the Read et al. question list (Appendix 1) which lasted approximately one hour. The project received IRB approval in July 2022. Interviews were conducted via a HIPAA-compliant institutional Zoom account between July and August 2022 (Zoom Video Communications, Inc. 2021). Verbal consent was obtained from each participant prior to beginning the interview. Eleven interviews were transcribed and ten were included for analysis (one participant withdrew consent after the interview). Participation was voluntary and not incentivized. Participants were asked to draw from the entirety of their time at UTHSC as well as their experience supporting the research of others, if relevant, including both peers and student researchers. Questions focused on participants' individual research and the data they produce, how they manage their data, if and how they budget for data management in grant proposals, their experience reusing or sharing data, and external, institutional, and library-based services they utilize or need. Participants were recruited using purposive sampling, their shared characteristic being that they conduct and/or support funded research at UTHSC. Research and Learning Service librarians and Information Technology colleagues helped to identify and recommend subject experts in Pharmacy, Medicine, Nursing, Graduate Health Sciences, and Health Professions (Table 1). The College of Dentistry was the only college not represented in this sample. The type of research conducted by participants was well representative of UTHSC faculty, and included basic science, clinical science, qualitative research, and secondary analysis (Table 2).

Table 1: Listing of UTHSC Colleges, number of research participants per College, and total number of faculty per College in FY 2023.

College	Number of Participants	Total Faculty Members (2023)
Health Professions	1	70
Graduate Health Sciences	1	5
Medicine	3	1206
Nursing	1	106
Pharmacy	4	66

Table 2: Listing of the types of research conducted by study participants, definitions for that research type, and the number of participants in each category that primarily conduct that type of research.

Research Type	Codebook Definition	Number of Participants
Basic Science	Includes theoretical and applied research. Basic science research—often called fundamental or bench research—provides the foundation of knowledge for the applied science that follows. E.g. Imaging, biometrics, animal studies, cell studies, genetics, biochemistry.	3
Clinical	Intended to produce knowledge valuable for the understanding of human disease, preventing and treating illness, and promoting health. E.g. clinical trials, observational drug studies, case studies.	4
Qualitative	Aims to gather and analyze non-numerical data in order to gain an understanding of individuals' social reality, including understanding their attitudes, beliefs, and motivation. E.g. interviews.	2
Secondary	Based on existing data, sometimes including bibliometric data.	1

Audio recordings were blinded to the investigators prior to Microsoft Word Online transcription. Blinded transcripts were then manually checked against the audio recordings for correction and intelligent transcription. Two investigators independently identified thematic groups during this transcription review process that would inductively build the initial codebook. Thematic codes were discussed, agreed upon,

and defined by the investigators and imported into NVivo. Investigators completed two iterations of open-coding to arrive at the final codebook and coded transcriptions for preliminary exploratory analysis.

Results and Discussion

After coding and analyzing participant transcripts, the investigators identified three major themes relevant to RDS planning at the University of Tennessee Health Science Center (UTHSC). These theme codes were cross-tabulated with the code "Need" in order to analyze the RDS needs of research participants. These included needs for: 1) "Support Services," 2) "Training & Instruction," and 3) Tools & Technology" (Table 3). The category of UTHSC Health Sciences "Library Perceptions," which includes services, resources, and personnel, was a final, overarching theme pertinent to RDS planning and was included in these results as a standalone category. Due to the low number of participants (10) in this initial scan, we do not anticipate that the results are generalizable. However, they provide an illuminating snapshot of researcher concerns to direct initial broad support offerings and further investigations. Included quotes have been edited for clarity.

Table 3: Listing of major theme codes relevant to research data services (RDS) and the number of interviews coded. Most are cross tabulated with the code "Need," except for a standalone code for participant "Library Perceptions."

Major Theme Code	Transcripts with Code (of 10)
Need/Support Services	10
Need/Training & Instruction	6
Need/Tools & Technology	4
Library Perceptions	6

Support Services

Research data "Support Services" was the most frequently coded major theme from the interviews, with all participants speaking to some aspect of this category (Table 3). Within our cross-tabulated theme of "Support Services/Need," 80% of participants spoke to clinical research specifically, and how the re-use, sharing, and organization of clinical data is a major pain point (Table 4). Clinical research was often discussed in contrast to basic sciences such as genetics, which participants perceived as having a more established and robust history of data sharing. One participant explained the historical discrepancy in data sharing between basic and clinical science:

> Traditionally we have the group which has genetic data, they're more …[established] because they
> need expensive computers and storage space and money [to do their work], so [data sharing] has

been in the making for quite a while. If they don't have access to these resources, their work is not happening.

But a lot of what we do in clinical research, the datasets are much, much smaller. They aren't complicated data structures, [like you would have] combining imaging data with genetic information. So traditionally we have solved [RDS needs] on an individual basis. Not much has been discussed about the joint needs of studies which have patient centered data from health encounters, or even clinical trial information, because [historically] the datasets were much easier to handle. I think it's good now that we look into what are the needs and how can we fulfill that.

Table 4: Listing of categorical codes that emerged from the Support Services/Need cross tabulation and the number of interviews meeting this criterion.

Support Services/Need Code	Transcripts with Code (of 10)
Clinical Research	8
Data Management - Activities & Per-sonnel	7
Data Management - Plans & Templates	6
Grant Funding Support	4
Data Analysis	4
Centralized Resources or Knowledge-base	3

Additionally, clinical science conversations included a desire for clinical data that is easier to query, extract, and re-use in secondary research, especially for student research purposes. However, there were also concerns around student re-use of clinical data, specifically due to a perceived lack of oversight for data security and destruction once the data extract request has been filled.

Most participants (70%) also strongly desired guidance around data documentation and organization, clearer workflows for working with healthcare datasets, and more robust institutional standards for research data security. With regards to data management plans (DMP), 60% of participants discussed a need for DMP templates or openly shared example plans, with some requesting specific data management personnel to write into their grant proposals to handle oversight. Grant funding services were also a topic of interest, with 40% of participants requesting more robust support for grant prospecting and proposal writing. A further 40% also discussed support for data analysis as a major need, including a better staffed statistics unit and more qualitative research expertise.

With regards to existing services and resources, several respondents (30%) discussed difficulties locating and accessing support at UTHSC. One respondent recognized that many services do currently exist, but given how difficult services are to locate or utilize they often turn to their own peer groups to fill in the gaps: "I feel like we have been very successful in figuring that stuff [RDS] out... but it has taken decades to do it and I'm not convinced that everybody realizes what resources are out there to make these things happen in a more efficient manner." Along the same lines, another participant explained that "there may be services here UTHSC that I'm just not accessing or aware of or seek out. I sometimes feel like there are things here that are on campus that I just don't know about." To this point, the dispersed and ad hoc nature of much of UTHSC research support emerged as an important consideration in many conversations.

Interestingly, one participant spoke to legal concerns about what an open data sharing environment could mean for future researchers, highlighting a different type of desired support:

> Something we're not thinking about is that the people who will be using this data in the future are lawyers and their analytics teams. For lawyers looking at something like adverse events and opioids, a researcher that collected the data cannot say they never looked at it...they are legally liable. [Legal teams] have the money and the personnel to pull and go through this data [in a way that academics cannot].

While legal support at this level is likely outside of the scope of typical university services, it is an important consideration for health science researchers as we move further into an open science environment. Other participants expressed similar anxieties around relinquishing direct stewardship of their data after repository submission, and how future use might be vetted, or not.

Training & Instruction

Conversations about "Training & Instruction" needs for both researchers and students centered on data science skills, primarily including data wrangling/cleaning, working with relational databases (querying in SQL, data extractions, and vocabularies), and the coding languages R and Python (50% of participants) (Table 5). One participant who teaches research skills to graduate students and often serves as a data specialist on faculty research said, "I have my students work with datasets because these are the skills that most people don't have. When researchers get these datasets [for re-use], they don't really understand what it's going to take for them to work with them." This touched on a common area of frustration for researchers, understanding how to query, extract, standardize, and securely work with healthcare data from institutional datasets.

Table 5: Listing of categorical codes that emerged from the Training & Instruction/Need cross tabulation and the number of interviews meeting this criterion.

Training & Instruction/Need Code	Transcripts with Code (of 10)
Data Science	5
How to Conduct Research	5
Human Subjects Data	2

Fifty percent of participants also spoke to research training more broadly and desired instruction for both faculty and student audiences on data collection methods, participant recruitment, research data management, setting up research workflows, data analysis, and study design. One participant even spoke to how students were increasingly choosing to re-use existing datasets rather than collecting their own data, and impact of this choice on their early-career research training:

> It's been challenging with [PhD] students who use an existing dataset—they miss the components of meeting people, collecting data, doing the hands on work that they normally would do. That's a major gap, unlike with the students I've advised who do their own research, from coming up with an idea, to identifying their participants, collecting the data, even data storage.

For 20% of participants, working with human-subject data in an open sharing environment brought up concerns around data security, including handling, storage, destruction, and transfer. A faculty researcher gave a relevant example, "One student study had an EHR [electronic health record] dataset floating around on a few different computers and I'm not sure how safe that is...we need a better plan or guidance for students on how to store their data beyond a password protected computer." Another researcher, who offers data analysis support, explained that although all UTHSC researchers receive training on PHI [protected health information], many often struggle to recognize it in their own data: "Every year I will have more than one individual, usually a resident or novice researcher, who will email us data [with PHI]. I know everyone is trained, but somehow it just escapes them." Similarly, knowledge about proper deidentification practices was a concern for another participant, who stated, "In the past I've asked for deidentified data from a researcher and received it and I'm like, yeah, age is an identifier. It's important to make sure that people remember that there are more identifiers than just name and date of birth." Participants explained that deidentification support will become increasingly important as they are asked to share as much scientific data as possible under the NIH DMSP.

Tools & Technology

Needed "Tools & Technology" intersected with several areas discussed previously, including the challenges of re-using large or complex datasets (Table 6). Expanding on the ways technology encompasses both "Support

Services" and "Training & Instruction," one participant clarified that better technological solutions alone will not solve research data problems, explaining "there's both a cultural aspect and a technical aspect [to data problems]." Another participant lent support this idea with an example about using UTHSC electronic health record databases, "You're given these database connections, but there isn't an understanding of what tools people can use. And then sometimes database administrators aren't realistic about what researchers can get up to speed with technologically." One proposed solution to the problem of working with these healthcare data was an institutional data enclave, which would provide a secure platform for easier data manipulation and analysis (20%) without having to download those data to a personal machine, a frequently identified security risk.

Table 6: Listing of categorical codes that emerged from the Tools & Technology/Need cross tabulation and the number of interviews meeting this criterion.

Tools & Technology/Need Code	Transcripts with Code (of 10)
Data Enclave	2
Institutional Data Repository	2
Datasets for Re-Use	2

Additionally, 20% of respondents hoped for a UTHSC data repository to share their research data, believing that an institutionally branded repository would enhance the University's reputation by showcasing our research. One explained:

> I think a data repository would be a great opportunity for the University to make sure that future data users are aware that the data originate from UTHSC… I think it is a really priceless opportunity for marketing and awareness.

However, another participant had a different view of institutional data repositories: "I think it would be overkill if UTHSC were to create a data sharing site where all our data are hosted. I don't think that would be necessary."

University sponsored access to a larger collection of purchased datasets for re-use was requested by 20% of participants, as was a centralized catalogue to aid researchers in locating such resources, again highlighting a findability issue. One participant explained how the high cost of access to large health care datasets was a sizeable barrier, even at the time of writing a funding proposal:

> As a large university it would be wonderful if we had access to [large datasets such as Medicaid], and to have contracts set-up where researchers like me could apply for access. It's not a not inexpensive to access these datasets, and many times it's a Catch 22. You need access to the dataset to be able to

get funding to get access to the dataset…if researchers could get access through the University that would be wonderful.

Perspectives on the Library

Participant "Library Perceptions" on the Health Sciences Library was the final major theme of interest to the RDS investigation (60%). While this was not a specific interview question, it often emerged organically due to the author and interviewer's affiliation with the Library. Overall, participants viewed the Library favorably. When discussing librarian expertise, one participant said, "You're going to love this—I wish we had more resource allocation to the Library. I don't think people realize it's not the library of 50 years ago." Some participants also expressed surprise that the Library was conducting data interviews and could have a role in RDS, explaining, "The fact that I'm having a discussion with you from the Library is very interesting, because I can see that librarians could be a potential group to provide [RDS] resources to faculty, much like IT provides technology support. There's this other whole piece that libraries could provide assistance with." These participants were often eager to learn more about how the Library could assist with their research, and frequently made the connection between Information Technology and the Library as similar in their mission to support users. However, where IT was seen as providing support for technical needs such as storage and software, through the interview process with the author participants began to see how Library expertise might fill service gaps in RDM tasks such as documentation and organization. One participant wrapped up their interview with, "I think instead of investigators reinventing the [RDS] wheel many times, it's better to have IT involved for some technical aspects and the Library involved for some of the other [data management and organization] aspects. I think that partnership could be a true service to researchers." Another researcher advocated for more Library involvement with campus clinical research support, stating, "There's still a lot to be done, and there's a whole lot that even IT doesn't know that happens informatics wise with the day-to-day operation of clinical trial, and all the different resources that we have. But I think for [RDM], the Library definitely should be an integral seat at that table if it's not already."

Finally, one participant specifically recognized librarian skills with structured vocabularies and writing complex search queries. As an example of how this might be mobilized, they discussed how "concept sets," which describe information in a patient's medical record, could help bridge a gap between research questions and data exports from large electronic health record (EHR) datasets (All of Us Research Hub, n.d.):

> I think that that's an area where the Library could show some leadership, making concept sets for diagnosis codes, so that if you know how to use the set, you could gather all the patients for a research project much easier than having to figure out the complex query you would need to write. That could help speed up data exports.

Service Mapping

An unexpected but welcomed outcome of the data interview process was the creation of an informal community of practice around assessing, improving, and delivering research data services at UTHSC. The interviews and purposive sampling put us in touch with a variety of stakeholders, such as Information Technology and a specialized IT research user group, the Office of Research, our statistical support group, the local Clinical and Translational Science Institute, and several department level research groups that provide authorship-based support to their peers. This shared interest in better understanding the research environment and needs of our researchers helped to position the Library as an engaged and impartial collaborator in the RDS space.
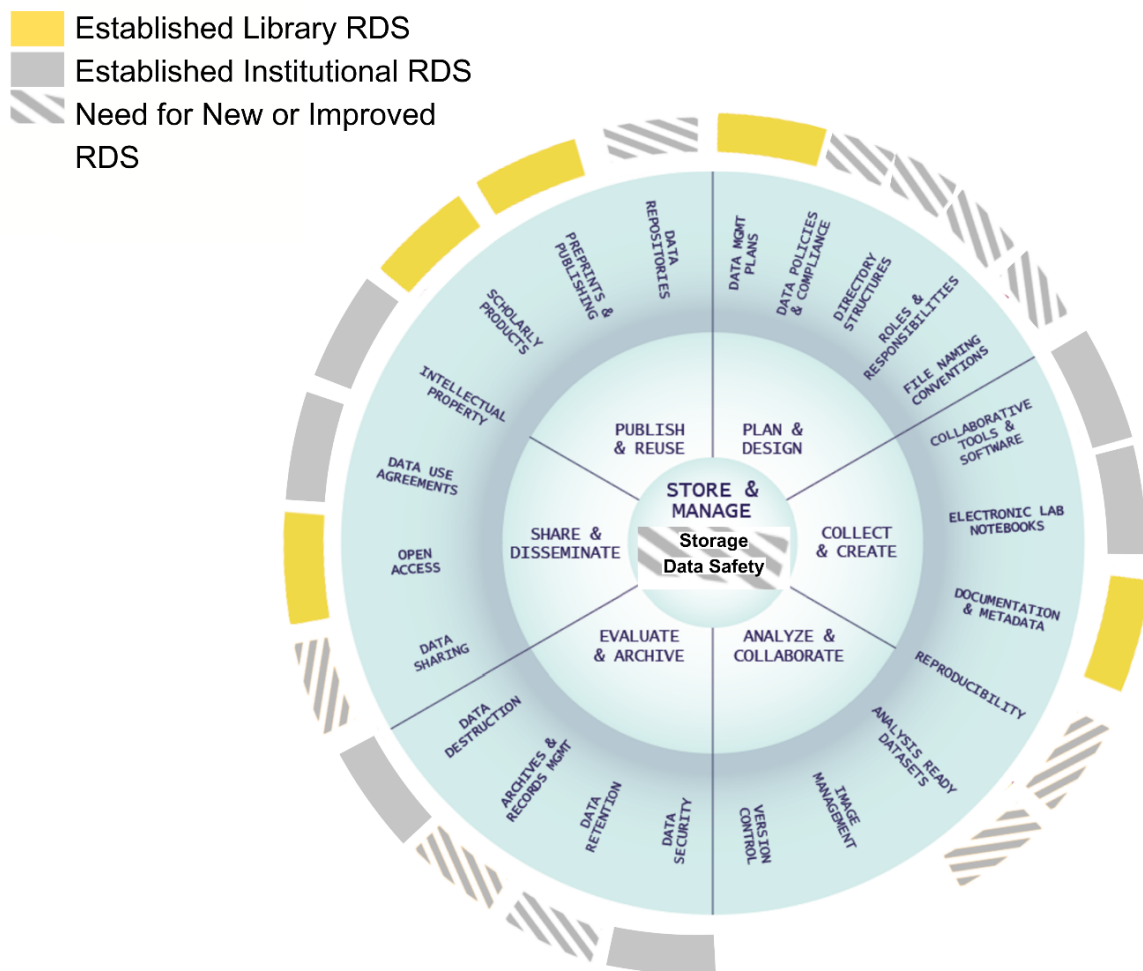
Figure 1: A modified version of Harvard's Biomedical Data Lifecycle, re-designed by Sarah Newell, highlighting research data services (RDS) offered by the Library (solid yellow bands) and other institutional stakeholders (solid grey bands). Areas of need for increased or new services, as identified through the interviews, are grey striped bands.

To help communicate interview results to interested UTHSC stakeholders, the author mapped findings from the interviews to Harvard's Biomedical Data Lifecycle, which visualized areas that are well supported by the Library or other institutional units, as well as areas of need (Figure 1) (Cioffi, Goldman, and Marchese 2023). The yellow bands indicate research data service areas currently supported by the Library. As evident in Figure 1, the Library is currently well positioned to support activities in the "Share & Disseminate" and "Publish & Reuse" sections. New support for two activities was established as a direct result of the interviews - "Data Management Plans" and "Documentation & Metadata." We began offering a DMP feedback service in January 2023 with the launch of the new NIH DMSP. Alongside the DMP feedback service, we now offer instruction and support for using the DMPTool as well as easy submission to the feedback service through the tool. Additionally, we offer data repository support such as identifying appropriate repositories and assistance with data deposits, including repository specific documentation and metadata.

Existing and well-established research data support is also provided by other UTHSC units. These activities are marked with solid grey bands. These services are primarily offered by the Office of Research and Information Technology. Within the Biomedical Research Data Lifecyle, the Office of Research offers assistance with the "Share & Disseminate" activities of "Data Use Agreements" and "Intellectual Property." Information Technology is primarily concerned with the "Collect & Create" and "Evaluate & Archive" sections. Interviewees most often spoke to IT support for activities related to "Data Security," "Data Destruction," and "Collaborative Tools & Software." Although, certain software are supported and administered by other groups, such as the Center for Biomedical Informatics (CBMI) and REDCap.

Lifecycle activities identified in the interviews as needing increased or new support are marked with the striped, grey bands. Often, these are activities that would benefit from a collabora-tive effort between two or more units on campus. Many of these activities are supported in part by informal research teams, such as a group from our Preventive Medicine department that assists with research design in exchange for authorship or co-investigator status. Other activities, such as "Analysis Ready Datasets," are supported in part by existing, formal units like the Center for Bio-medical Informatics, but are also marked as an area needing increased support. As an example of the need for a collaborative approach to many research data services, the activities required for "Analysis Ready Datasets" connect all three major themes from the interviews: "Support Services," "Training & Education," and "Tools & Technology." The desire for re-usable and accessible patient health datasets was discussed in many ways during the interviews, touching on everything from data wrangling instruction, to preset health condition queries for data exports, to technological solu-tions like enclaves. One interesting proposal from this area was that librarians could leverage their ontological expertise to help create "concept sets" for the NIH All of Us Research Hub, an example of leveraging key information science skills to standardize data extracts. Overall, however, data re-usability is clearly a large topic and will require collaboration with other RDS units, namely Re-search IT and data owners. The author identified these activities as opportunities for increased col-laboration with our campus partners and a worthwhile target for future RDS work.

Conclusion

The landscape of research data management and support services is evolving rapidly, driven by the increasing demands of open science and data sharing requirements from major funding agencies such as the National Institutes of Health (NIH). This study explores how the UTHSC Health Sciences Library worked to discover and meet the emergent needs of this changing environment. Findings from the data interviews reveal a variety of interconnected needs and challenges faced by researchers at UTHSC, particularly in the realm of research data services (RDS). As research becomes more data-intensive, the need for robust support in data management, sharing, and analysis is paramount. This is especially true in clinical research, where the complexities of handling sensitive healthcare data present unique challenges.

"Support Services" emerged as a critical need among research participants. The desire for guidance in data documentation, organization, and the development of data management plans was evident. Researchers also expressed a need for more substantial support for grant funding, data analysis, and centralized resources to navigate the often fragmented landscape of research support on campus. "Training & Instruction" was identified as a key component of RDS needs. Participants expressed a strong desire for instruction in data science skills, including data wrangling, database querying, and coding languages like R and Python. Additionally, training in research methods, data collection, and ethical considerations for working with human-subject data were highlighted. Finally, with regards to "Tools & Technology," researchers called for easy-to-use technological solutions to facilitate data manipulation, analysis, and secure data storage. An institutional data enclave and a data repository were proposed as solutions to enhance data accessibility and security. Furthermore, researchers expressed a need for access to a broader range of datasets for re-use, as the cost of acquiring large healthcare datasets could be prohibitive to their work.

The data interviews highlight the diverse needs of researchers and underscore the importance of collaboration among various campus stakeholders, including the Library, Information Technology, Office of Research, and other RDS units. We anticipate needs around data sharing will continue to change as funder mandates mature and researchers build their own expertise. RDS initiatives will likely be most successful if they are adaptive and embarked upon in close collaboration with existing institutional expertise and resources. As we move forward in the era of open science and data sharing, addressing these needs agilely and building strong partnerships will be instrumental in advancing research at our institution and ensuring compliance with evolving funding agency policies. The journey toward robust research data services at the University of Tennessee Health Science Center is ongoing, and our Health Sciences Library is poised to play a pivotal role in this process.

Data Availability

Interview questions are available under the article Supplementary Files:

Appendix 1: Interview Guide

Acknowledgements

Competing Interests

The author declares that they have no competing interests.

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