

NF Research Tools Database: An experimental resource database for the neurofibromatosis community

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Highlights

- We are developing a centralized resource database for NF1 research tools, including animal models, cell lines, antibodies, genetic reagents, and biobanks.
- The research community will be able to contribute feedback, usage notes, and other observations about these tools to the database.
- We are recruiting testers to participate in an upcoming evaluative design study to ensure that this resource is useful for the research community.

Background & Introduction

- When the Gilbert Family Foundation (GFF) started to fund investigators with little or no prior experience in NF1 research, it became evident that research progress was impacted by the challenge of identifying, evaluating, obtaining, and/or creating the tools required for their research.
- While a variety of databases exist for investigators to find useful research tools these databases are usually:
 - Specific to the type of resource,
 - Too broad in scope, and/or
 - Do not include newly developed or unpublished models
- To accelerate NF research, we are building the **NF Research Tools Database**, a database and companion web application to store and explore information about model resources specifically relevant to the NF community.
- The database will include key attributes for each resource and contributed observational data from publications and the research community.
- The database development consists of three phases (Figure 1):
 - Design (**current phase**): Generation of a prototype database website.
 - Pilot: Visitors can search and explore the contents of the database through the website.
 - Long-term Development: Members of the NF community will be able to submit resource attributes or observations through a user friendly submission process.

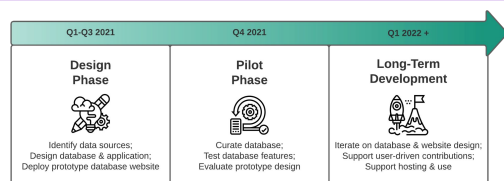


Figure 1. Overview of the phases and timeline of development for the NF Research Tools Database.

Acknowledgements

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Approach

Evaluating External Data Sources & Prior Work

- GFF developed an alpha version of the database, incorporating tools utilized within GFF research programs and soliciting feedback from their awardees on how to best classify and characterize each tool.
- Sage then conducted a review of websites containing NF-related tools to identify data sources to further populate this database.
- Collectively, these efforts have revealed a complex ecosystem of NF resources, where some existing repositories, such as the Resource Identification Initiative (RRID), pull data from other sources.
- The NF Research Tools Database will coalesce NF-relevant experimental resources into a central database (Figure 2).

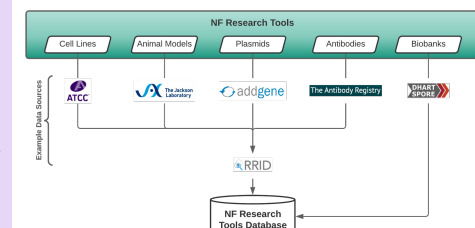


Figure 2. Expected flow of information on cell lines, animal models, plasmids, antibodies and biobanks into the NF Research Tools Database.

Designing a Data Model

- Using the external data sources as a model, we enumerated important attribute fields for each research resource.
 - A copy of the latest summary of attributes for each resource type can be found [here](https://nf-osi@sagebionetworks.org). Please contact nf-osi@sagebionetworks.org if you have any questions or feedback on this. Your feedback is welcome!
- Efforts are ongoing to translate the attributes for each resource type into an integrated data model for the database to satisfy the anticipated use-cases (Figure 3).
- This data model will include observational data provided by the research community such as reviews, usage notes, and pathological observations.

Identifying Use-Cases

- Relying on our experience working with the experimental research community, we developed a series of “user stories” defining expected scenarios that describe how potential stakeholders would use the database.
- User stories help to define use-cases for the database, and ensure that the resulting product fulfills those use-cases.
- For example, bench scientists, clinicians, and bioinformaticians might want to “view which driver mutations a disease model has, so that they know if an animal model listed in the database has a specific genetic mutation they are interested in studying”
- To complement each use-case, we generated an example “competency question” that the database must be able to answer to fulfill the use-case (e.g. “For resource X, display all gene/protein mutation information such as NF1 mutation status, mutation type, and how the mutation was induced, if it was”).

Prototype Design & Evaluation

- Based on the use-cases, efforts are ongoing to design a simplified mockup of the web application (“wireframes”) for the first round of product design. The wireframes will then be developed and refined to create a prototype design for the database website.
- Following deployment of the prototype database website, we will engage members of the NF community in an **evaluative design research study**.
- This study will help determine if the design and features of the database website meet the goals and needs of its users, informing improvements and long-term development goals for the database (Figure 4).
 - Study participants will participate in brief guided interviews to test and evaluate the usability and design of the website.
 - Participants will then be provided a gift card as a thank you for their participation.

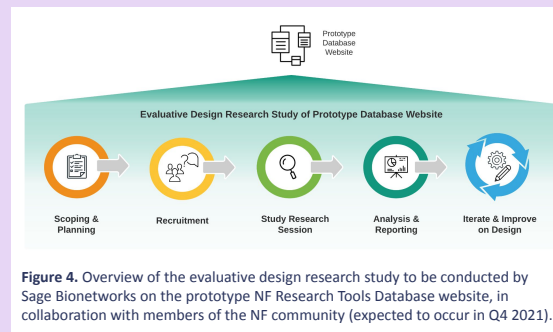


Figure 4. Overview of the evaluative design research study to be conducted by Sage Bionetworks on the prototype NF Research Tools Database website, in collaboration with members of the NF community (expected to occur in Q4 2021).

Conclusions & Future Directions

- GFF and Sage Bionetworks have made significant progress in developing a prototype tools database and companion web application for NF1 research resources. This resource could be a one-stop-shop for learning about the various experimental tools that have been generated by the NF1 research community
- After the prototype phase, we plan to expand the scope of this database to include NF2 and schwannomatosis-related resources
- We encourage feedback from the research community, particularly:
 - What NF1-relevant animal models, cell lines, antibodies, genetic reagents, and biobanks you would like to see listed in the database.
 - What types of research resource attributes you consider when, for example, selecting a cell line for an experiment.
 - Whether you would be likely to contribute observational information about a research resource to a database like this.
- We are recruiting testers to participate in an upcoming evaluative design study. Please contact nf-osi@sagebionetworks.org if you are interested in participating in this study (Q4 2021) or contributing information about an NF1 research resource!