Choosing What Matters: Data Collection

Know your why

Think of data like ingredients in a recipe. You don't add paprika to your pancakes (I hope!). Review all the questions you currently ask clients and consider why you are collecting each piece of data and what it will be used for. What is information you need to know to provide services or improve your programs and what is information you do not need to know? Document why you are collecting data so you can share that with coworkers and clients.

Remember, less is more

When you're brainstorming about what you ask clients and why, remember that less is more. Stick to only asking for information that will help your organization achieve its goals. This approach means less data collection burden on you and less burden on clients.

Keep it standardized

Standardizing data collection is like having a secret sauce for better data quality. While it's tempting to experiment with different approaches, like constantly changing the questions you ask clients, it is important to have some consistency. Consistent data collection allows you to track client progress over time and makes it easier to use that data.

Data Audits

While it is important not to change processes too often, it is recommended to set aside time to review existing processes on a yearly basis and update them if they no longer make sense.

Keep it client-centered

Be transparent with clients about why you are collecting data and how you will use it. Where possible, invite them to the table when changing or updating data collection tools so that their voices are included. Keep channels open for client feedback in all aspects of data collection. When you can, share back any analysis from the data so they can see the impact of their stories.

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Data Analysis Cheat Sheet

As always, know your why

Think of your organization's strategic priorities and funding and reporting requirements. How can your analysis support those priorities and requirements? For example, if your organization’s priority is to teach clients skills needed for them to live independently, then your analysis might look at whether client life skills improve by the time they leave the program and where additional support might be needed.

Garbage in, garbage out

Just like cooking with subpar ingredients can spoil the dish, bad quality data can ruin your analysis. Ensure your data collection tools, even trusty Excel spreadsheets, have some data checks in place, like not allowing someone to enter in that they are 200 years old (!). Your REDCap systems are already set up to have those checks in place. You may also want to examine the data yourself for odd values before you analyze it.

Train and empower your team

Great cooking requires skill (as a bad cook, I can confirm this one) and you need someone with the expertise to take on the endeavor. Invest in your team to build the skills needed to analyze data and answer the questions that you identified. If resources are constrained, utilize free or low-cost data analysis tools and seek pro bono support from volunteer data professionals like Data for Good.

Simplicity is your ally

Simplicity is your ally when your resources are limited. From crafting basic bar charts to using summary statistics like mean and median, these simple analyses can show you trends in your data. Remember, simplicity doesn't mean sacrificing depth—by focusing on clear visualizations and fundamental statistics, you can gain insights that do not require a lot of resources in terms of time and expertise and that can still drive informed decision-making.

Data Management Cheat Sheet

Clearly defined roles

It is important to have clearly defined roles in your organization around data management. Who will enter the data? Who analyzes the data? Who manages reporting? Who deletes old data? Who manages access to the data and prevents unauthorized access? There need to be clearly defined roles so data is being properly managed and stored. There should be at least one person in the organization who has complete administrative access to the data and can assign data access.

Documentation: We hate it, but we need it

Keep a track of the data you are collecting, storing and using in the form of a data inventory (which is basically like a catalog that helps you keep track of the data you collect, where it goes and how it is being used). Also, document data roles - e.g., who is accountable for what tasks - so that clear accountability exists and processes are streamlined. Documentation also helps with onboarding new staff when there is staff turnover.

Training staff for data collection and use

Make sure staff are trained on data entry so that data is entered consistently across staff and data quality is maintained. If processes are updated in annual data audits, include additional staff training to support that change management.

Set up user access controls

Set up user access controls to reflect the roles that you defined for data collection, use and management. Not everyone in your organization needs to be able to access or edit all the data you collect. Limiting access to the data also protects client confidentiality and privacy.

Backup your data regularly

Back up your data regularly by downloading it on a secure organizational device that is password protected and not accessible to anyone aside from a few trusted staff members.

Data Retention and Deletion Cheat Sheet

Data retention for clients who have left the program

Agencies need to abide by legal, and regulatory requirements around the length of time for which they can retain identifying client data. Once a client is in the process of leaving a program, you will need to fill out their planned or unplanned exit forms (based on how they left). The completion of these forms in REDCap will push all their data from the "active client" dashboard to the "old clients" dashboard. You will no longer be able to see their data in the active client dashboard. This setup allows you to keep their data in REDCap for the length of time (e.g. ten years) that you are allowed to keep their identifying data. **Do not forget to fill out exit forms when clients leave the program.**

Data deletion

Once the duration of time that you are allowed to keep specific client records has passed, you will get a notification on your email from REDCap alerting you to the fact that you need to delete specific records. REDCap will not automatically delete those records for you. You will need to log into REDCap and delete those records. Based on legal and organizational requirements, you might choose to download aggregate data to understand the impact of your program before you delete individual identifying data.

Secure data deletion

If you have been storing backups of your data on your organizational device, it is important to make sure you delete those copies of the data as well when you've reached the duration for which you could keep identifying data. To ensure that data is permanently removed and cannot be recovered, you might consider using data deletion software that make it difficult to retrieve deleted data. If you have copies of the data in physical format (which you are likely to have as you transition into using the REDCap system), you would need to destroy and shred those too.

REDCap Cheat Sheet

As you use the REDCap system, here are a few key things to remember:

- **All** data collection that happens leading up to a decision on client application will need to be documented in the application form in REDCap. This would include data collected through the application form itself, data from follow-up interviews, information from references and finally the application decision itself.
- Once a client is accepted into the program, one of the first steps would be to ensure that consent forms are signed before any additional information is collected.
- Consent needs to be informed, which means that staff should be trained to clearly explain the purpose of data collection, how long data will be kept for and what it will be used for.
- Once those forms are complete, Needs Assessment forms can then be completed. These do not need to be completed in one session and can be filled over several weeks to reduce the burden of data entry on clients and staff. Program forms, such as case notes and incident reports, will also be filled out during the course of the program.
- Some of the forms are *repeating instruments* - this means that you can keep adding more of those forms for the same client by following the process outlined in the user guide. An example of a repeating form in your REDCap system is the case notes form.
- You do not need to fill out all forms in the system. The system is designed to be flexible and some forms may not apply to particular clients (e.g. the pregnancy form for clients who are not pregnant).
- Make sure to get familiar with the different dashboard views. The dashboards are set up to give you quick access to data that you need. For example, you can print off medical data for a client from the "Medical Information" dashboard to give to EMS in the case of an emergency. The active client dashboard is where you will spend your most time entering in new client data.

REDCap Cheat Sheet Cont.

- Make sure to get familiar with the different dashboard views. The dashboards are set up to give you quick access to data that you need. For example, you can print off medical data for a client from the “Medical Information” dashboard to give to EMS in the case of an emergency. The active client dashboard is where you will spend your most time entering in new client data.
- When a client is in the process of leaving a program, you will need to fill out their planned or unplanned exit forms (based on how they left). The completion of these forms in REDCap will push all their data from the “active client” dashboard to the “old clients” dashboard. Do not forget to fill out exit forms when clients leave the program.
- Many of the REDCap forms have questions that have a branching logic to them - e.g., if you select yes for a question, an additional question will appear. In this example, if you selected yes, filled out the follow-up question, but then changed your original answer to a no, it will delete any information that you captured in the follow-up question.
- Some of the forms are also connected, e.g. the Needs Assessment: Child Health and Wellness and the Needs Assessment: Parenting forms. If you entered in a child’s name in the Child Health and Wellness form, it will make additional fields appear in the Parenting form asking for father and custody details. If you remove the child’s name from the Child Health and Wellness form, REDCap will alert you that this will delete information in the Parenting form. If you click ok, this deletes the child’s information from the Parenting form.

REDCap Cheat Sheet Cont.

- Connected to the point above, for clients who are pregnant, it is advisable to enter in father details in the Parenting form even before the baby is born. The Parenting form is set up to allow you to enter father and custody details before the baby is born and before you add any information into the Child Health and Wellness form for the baby specifically. However, please remember to enter in baby details in the Child Health and Wellness form once the baby is born. It is important to have this and other forms be as complete as possible.
- Questions with a red “*must provide value” written under them are questions that require a response. If you are filling out forms within REDCap, you can skip those questions, although REDCap will remind you to fill them out before you leave a form. You can choose to ignore that reminder. However, if you’re filling out a form as a survey (such as an application form), then you cannot submit the form without filling out all the required fields.
- Using the new REDCap system gives you significantly more control over your data collection processes compared to other software or paper-based methods. REDCap's main advantage is its flexibility, allowing you to easily create, update, and modify data collection tools and surveys as needed. If you find that your tools or processes need updating, you can do so directly within REDCap. However, it's important to have clear organizational procedures in place for making these changes to ensure consistency and accuracy. It is also important that only a few select individuals in the organization have the ability and authority to make those changes and updates.