

# REDCap Basics for Syringe Service Programs

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**SHaRP: SUPPORTING HARM REDUCTION PROGRAMS**

UNIVERSITY *of* WASHINGTON

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## Statement of Purpose

This is a short guide for harm reduction programs and syringe service programs (SSPs) considering using REDCap for their data collection and management created by the Supporting Harm Reduction Programs (SHaRP) team at the University of Washington. It reviews basic information about REDCap, strengths and challenges for use with SSPs, and the main ways to access REDCap.

The SHaRP team has considerable experience using REDCap and working with organizations to build out REDCap systems. However, given the wealth, variety, and ongoing evolution of guidance on REDCap's capabilities, this guide should not be considered comprehensive or airtight.

Finally, this is not a promotion or endorsement of one particular company, software, or product by the Opioid Response Network (ORN), SAMHSA, or the SHaRP team. Further, this is not a recommendation of REDCap as the best software for SSP monitoring and evaluation. There is no one software solution that will work for all SSPs. Many complex factors figure into what software choices will work best for each individual program.

## What is REDCap?

Research Electronic Data Capture (REDCap) was originally created by Vanderbilt University for clinical research data collection. REDCap cannot be installed on your computer like traditional software; it needs to be hosted on a server. It is **free** to non-profit organizations who agree to [the license terms](#)<sup>1</sup> through the REDCap consortium. Often the main costs associated with REDCap are the server and IT support, not the software itself. Read more information about this [below](#). A major benefit of REDCap's system design is that each independent organization with a REDCap server has total control of their data. Read more about it on the [REDCap site here](#)<sup>2</sup>. [Here](#)<sup>3</sup> and [here](#)<sup>4</sup> are some resources to learn more basic information about REDCap.

## REDCap Strengths for Harm Reduction Programs

Powerful platform for data collection and data management

REDCap is a powerful platform for data collection and data management. It has many tools and features for different ways to collect data, and it is updated regularly with new features. REDCap uses 'forms' and 'surveys' to collect data. The main difference between forms and surveys is that only users with a log-in can fill out a form, similar to direct data entry on your program's computers or encounter logs. Surveys can be accessed via a link that can be filled out by anyone who has the link, like a digital version of a paper survey you would hand a participant.

Simple REDCap forms and surveys can be easy to build and do not require coding knowledge. REDCap has robust functionality for different types of fields (e.g., multiple choice, fill-in-the blank, numerical) and skip patterns. REDCap can meet the data collection and management needs of the vast majority of SSPs and harm reduction organizations. However, compared with survey-specific software options (e.g., Qualtrics) REDCap has some limitations. It can get complicated to run very long surveys with skip patterns based on multiple variables, for instance, and programming skip logic is a little more complex than other programs.

REDCap is designed for unique data collection (e.g., each client has a unique ID), as that is more common in clinical research. It can be used for anonymous data collection as well (i.e., no unique ID).

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<sup>1</sup> <https://projectredcap.org/partners/termsofuse/>

<sup>2</sup> <https://projectredcap.org/about/>

<sup>3</sup> <https://ctsc.health.unm.edu/redcap-info/>

<sup>4</sup> <https://www.youtube.com/watch?v=FTIxEfURgz4>

### Offline data collection

REDCap allows for offline data collection via the REDCap mobile app for smartphones and tablets. While offline data collection is possible, ensuring that the most up-to-date version of your project is on the mobile app requires a fair amount of management. Data collected on the app is not automatically pushed to the server once the tablet or smartphone is on Wi-Fi. Instead, it must be done manually by connecting to Wi-Fi, opening the app, and sending the data to the server. Once the system is learned, it isn't perfect, but it is manageable. Very few other software options offer offline data collection.

### Potentially low-cost

As mentioned above, and discussed in more detail below, REDCap is free. The main costs associated with REDCap are the cost of a server and whatever IT support is needed to maintain the server. The cost of a server can vary significantly based on if it is a cloud-based server or a physical server, and on the size of the server. Many organizations can access REDCap for free through [a local university or health department](#)<sup>5</sup>. The pros and cons of that option are discussed more [below](#).

### Potential for data privacy and security

If used correctly, REDCap can be a secure data collection and management tool. REDCap is HIPAA compliant and can be used to store protected health information (PHI) if need be. When organizations have their own physical server, they are literally in control of their data. However, the server does need to be set up correctly and properly maintained to reap the security benefits. A virtual or cloud-based server can also offer data security, however, you become reliant on the host, most likely Amazon or Microsoft. This is discussed in more detail in the [sections below](#). Below is a short description of some of REDCap's main security features.

REDCap has strong user privileges management tools that allow for specific and granular control of who has access to data and information stored in each REDCap project. The user management allows for careful management of who can enter data, see data in the system, edit data, export data and more. REDCap also has an audit trail feature in order to see who has done what actions in the project. Data can be collected into REDCap either by individuals with their own individual logins or through a survey for which a login is not needed. More information about REDCap's security features can be found in their [technical overview](#)<sup>6</sup>.

REDCap is HIPAA compliant and can be used to store protected health information (PHI) if needed.

When making forms and surveys, fields in REDCap can be marked as 'identifiable data.' Upon data export, users have the option to export the full dataset with identifiable data or a reduced dataset where any data marked as identifiable is removed.

### Relatively easy to learn to use and tons of free resources

REDCap is not "open source," however it does have much of the spirit of open source in that there are a lot of resources online to teach yourself how to use REDCap. Many universities use REDCap and offer free tutorials on varying aspects of REDCap management, design, and use.

REDCap does not require any knowledge of coding to create forms or surveys. While the design is not hard to learn, REDCap is not focused on design. Sometimes it can feel clunky or less intuitive than other for-profit software options.

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<sup>5</sup> <https://projectredcap.org/partners/>

<sup>6</sup> <https://projectredcap.org/wp-content/resources/REDCapTechnicalOverview.pdf>

### Plays well with other software for data analysis and visualization

REDCap is designed for data collection and management, and not for data analysis or visualization. It has some rudimentary data analysis, reporting, and visualization tools. However, REDCap does export data into various formats that work well with other data analysis and visualization tools and software.

### Easy to transfer REDCap projects

It is relatively easy to transfer REDCap projects and data between different organizations' REDCaps. REDCap has functionality to download the 'data dictionary' which allows you to download the forms and design of a data collection system and also the data from the project. Both can then be re-uploaded into a new REDCap. For example, if an organization starts using REDCap with a local university and then wants to switch to their own server, they can relatively easily move their project.

## REDCap Challenges for Harm Reduction Programs

### Designed for research, not ongoing program evaluation

The main challenge SSPs may experience using REDCap is that REDCap was designed for clinical research. So, some of its features are not intuitive for ongoing program evaluation.

For instance, once data collection is started it can be difficult to change how data is collected without erasing or changing the data that has already been collected. This feature is a strength for clinical research, as uniformity in the dataset is important. However, it can be an obstacle when REDCap is used for ongoing program evaluation, which is how many SSPs use REDCap. While it is possible to navigate this in a way that does not erase or change the data, it has to be done in specific ways.

Also, REDCap is designed for unique data collection (e.g., each client has a unique ID), as that is more common in clinical research. It can be used for anonymous data collection as well (i.e., no unique ID).

### Minimal tools for data analysis and visualization

REDCap is strongest in data collection and data management and weakest in data analysis, reporting, and visualization. As noted above, REDCap has some data analysis functions and the ability to program some basic data reporting, but it is limited in its functionality.

However, REDCap is designed to export a database into a variety of forms (excel, CSV, SPSS, SAS, R, Stata, CDISC) that can plug into a variety of other data analysis and reporting options, including into dashboards like Looker studio (formally Google Data Studio) and R Shiny. Besides excel, most of the analysis tools listed require knowledge of statistics and/or coding to use them. Organizations with a staff member, consultant, or academic partner with statistical coding skills will be better situated to tap into potential efficiencies and insights from regular data analysis.

### Potential need for IT support and server support

Since REDCap is not traditional software and needs a server, it has higher IT needs than traditional software in order for it to work (both functionally and to achieve its full data security potential). Most small SSPs do not have internal dedicated IT personnel that have the knowledge to build or maintain a server. There are options for hiring IT consultants or external IT support that may be able to provide services at a lower cost than a full-time internal employee. There are two other main options for organizations that do not have internal IT knowledge. One is [accessing REDCap via another organization](#), especially a university or other large institution. They would have a dedicated IT department that maintains and updates their REDCap server and system. The second option is paying to use [Vanderbilt's server](#), where they maintain and update the REDCap server and software.

Cannot be used as an electronic medical record (EMR)

REDCap cannot be used as a clinical record system and does not replace an electronic medical record (EMR). This is part of the licensing agreement, i.e., anyone using REDCap agrees that they will not use it as an EMR. It is best used for collecting programmatic data and/or research. The system occasionally goes offline for updates, and thus cannot function as an EMR.

REDCap can be used for case management, for example entering notes about a visit, however, it can be a bit clunky.

## Accessing REDCap

As mentioned previously, REDCap is not like traditional software. In order to run REDCap it needs its own server. There are ways to access REDCap without running your own server. There are three main options for accessing REDCap are described below.

It is relatively easy to transfer REDCap projects and the data between REDCap hosts, so know that you are not necessarily locked into one option forever once you start a project.

### Option 1: Become a Consortium Partner

REDCap is not software that you install on a computer; it requires a server to operate. This can be a physical server, a virtual or cloud-based server, or you can pay Vanderbilt a monthly fee to use their server ([this is described separately in option 2](#)). There are benefits and drawbacks to all three options. REDCap provides a [Technical Overview PDF<sup>7</sup>](#) that outlines many of the technical requirements and licensing agreements.

If you decide to become a consortium partner you will need to agree to [the license terms<sup>8</sup>](#) and you will need to decide what server option is best for your organization.

#### Physical Server

One option is to obtain and maintain a physical, or on-premises, server that can host REDCap and store your data. This option is likely one of the most secure from a data standpoint, since you are fully in charge of your own server. A physical server can be expensive and require a dedicated IT team to maintain. However, for some organizations, the security gains are worth it (e.g., federally qualified health centers).

[An estimated cost for a physical REDCap server is approximately \\$10,000<sup>9</sup>](#). This is an estimate, and it could be very different your organization depending on a variety of factors. Another cost to consider is the need for an IT staff or consultant, either an internal or external position.

When considering an IT staff member, you will likely need someone who understands servers; can identify the appropriate equipment for your size organization and data needs; can purchase and set up the equipment; and who can maintain the server. This support could be an internal staff position or an IT consultant.

#### Virtual or Cloud Based Server

Another option is a virtual or cloud-based server. This means that the server company is hosting your storage space, and they may have some access to your files. They may also be able to stop hosting you at any time or shut down your server. These are unlikely but have happened ([e.g., Amazon and Parler<sup>10</sup>](#)).

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<sup>7</sup> <https://projectredcap.org/wp-content/resources/REDCapTechnicalOverview.pdf>

<sup>8</sup> <https://projectredcap.org/partners/termsfuse/>

<sup>9</sup> <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4287671/>

<sup>10</sup> <https://www.npr.org/2021/01/21/956486352/judge-refuses-to-reinstate-parler-after-amazon-shut-it-down>

[Amazon's AWS Quick Start<sup>11</sup>](#) and Microsoft's [Azure Quick Start<sup>12</sup>](#) have provider-specific information about how your organization's IT department can quickly deploy a production-ready REDCap environment through either of these providers. Cost based on these cloud servers will vary by organizational needs. Costs of the cloud server itself may go up over time as the amount of data in the cloud increases. One small CBO-based SSP with locations in several small cities reports about \$20 a month for the server cost, they did not report their consultant IT costs. Although, IT staff or consultants would likely need less hours to build and maintain a virtual server than a physical server.

If you are storing protected health information (PHI) in your REDCap, you need to have a business associate agreement between your organization and the cloud service provider.

### Option 2: Vanderbilt's Server

Vanderbilt's own REDCap server ([redcap.vanderbilt.edu](http://redcap.vanderbilt.edu)) can be used for a monthly fee. This option is the most like using REDCap as software, since Vanderbilt deals with the technical server stuff and allows you to access REDCap.

For many organizations, we believe this is the best option. While hosting your own cloud-based server is likely cheaper, it is not taking into account the associated IT costs. It is not always clear, but this option seems to bill by 'REDCap project.' So, some organizations might have multiple projects and they'd need to consider that when estimating their cost.

The 2024 fees are [listed here<sup>13</sup>](#) as \$117.70 a month for non-profit organizations. The Vanderbilt REDCap team also offers a fee for service (a la carte) for customized programming at \$94.60 (assuming per hour).

[Fill out this form<sup>14</sup>](#) or contact Vanderbilt at [redcap@vumc.org](mailto:redcap@vumc.org) for more information.

### Option 3: Find a Consortium Partner

If an organization does not have the funding and/or IT support to host their own server, they can access REDCap through another organization in the consortium. Many universities have access and will make access free to local nonprofits and community-based organizations.

The main benefits of this option are:

- Usually, free access to REDCap for organizations without the funding and/or IT support to host their own project.
- Can lead to building relationships and partnerships with other local organizations.
- Management of the REDCap server and updates are done by the other organization.
- It is easy to move a REDCap project and its data from one host to another, so it does not have to be a permanent decision to have them host.

The main drawbacks of this option are:

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<sup>11</sup><https://github.com/vanderbilt-redcap/redcap-aws-cloudformation#deploy-a-redcap-environment-on-aws-using-automation-and-architectural-best-practices>

<sup>12</sup> <https://github.com/vanderbilt-redcap/redcap-azure/blob/master/README.md#arm-template-for-redcap-automated-deployment-in-azure>

<sup>13</sup>

[https://redcap.vumc.org/surveys/index.php?pid=22205&\\_passthru=DataEntry%2Ffile\\_download.php&type=attachment&field\\_name=intro&hidden\\_edit=0&record=1&event\\_id=41898&doc\\_id\\_hash=6b3e7825f058abcf2000ac943855e9717bdc60d&instance=1&id=10484316&s=qHNLukTCfY](https://redcap.vumc.org/surveys/index.php?pid=22205&_passthru=DataEntry%2Ffile_download.php&type=attachment&field_name=intro&hidden_edit=0&record=1&event_id=41898&doc_id_hash=6b3e7825f058abcf2000ac943855e9717bdc60d&instance=1&id=10484316&s=qHNLukTCfY)

<sup>14</sup> <https://redcap.vumc.org/surveys/?s=qHNLukTCfY>

- There will be some IT personnel at the hosting organization that will have access to your data. Most often there are rules that restrict them from going in without your asking or doing anything with your data, but it is important to clarify those rules and procedures.
- There can be more administrative work involved, for instance communicating about adding or removing users, creating new projects, and in some instances editing forms or surveys.
- You have less control over your projects depending on how the partner runs their REDCap. Different organizations allow users to have different levels of control over their projects.
- You may lose access at some point if they decide they are no longer able to host you.

To look for a local consortium partner, like a local university, nonprofit, or local health department [search this list](#)<sup>15</sup>.

Here is a list of questions you may want to ask when considering a REDCap consortium partner:

- Cost and support
  - What are the costs, if any, related to REDCap access?
    - Is there a fee? How is the fee calculated?
  - Does the organization offer any REDCap support (help with a problem, office hours, etc.)?
    - Is there a cost to access the REDCap support?
- Functionality
  - Are there limits on the number of REDCap projects you'll support?
  - Will you be able to make changes and edits to forms in your project (for both projects in development and in production)?
    - If not, what is the process for making changes?
- Users
  - What is the process for setting up, adding, or removing users on a project?
    - How long does it usually take for these changes to be made?
  - Are there limits to the number of users you can add?
- Data Access and Privacy
  - Who would have access to our data and projects?
  - What kind of rules govern them? When could they come into our project without asking us?
  - Who owns our data in the project?
  - If someone (i.e. a researcher, law enforcement) wanted to access our data or project from outside our organization, how is that dealt with?
  - What would happen if you received a subpoena for our data?
  - Can you confirm that no research, analysis, or publications will be done using our data?
  - If we needed to move our REDCap project to another host, can you confirm you'd give us our data dictionary and data? What is that process, and how long would it take?

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<sup>15</sup> <https://projectredcap.org/partners/>