




The Influence of Redcap in Improving the Quality of Data in Sickle Cell Medical Research Program: The Case of Sickle Cell Program at Muhimbili National Hospital

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Abstract:

The study examined the influence of REDCap in improving the quality of data in sickle cell medical research program. The study used descriptive research design whereas both qualitative and quantitative approaches were used where a cross-sectional design was employed to collect information at one time in particular point. A total of 52 questionnaires with closed-ended questions were distributed. Primary data were collected through survey and in-depth interviews. Data were analyzed by using SPSS which simplified process of data analysis; the program identified the position of the variables and multiple regression analysis. The study found that there is effectiveness of REDCap in improving the quality of data in sickle

cell medical research program in the sense that REDCap has effectively facilitated the collection of all necessary variables and essential information for research purposes. The study concluded that REDCap plays a significant role in improving the overall data quality in the context of sickle cell medical research programs. The study suggests that stringent quality control procedures should be implemented to ensure the accuracy and reliability of data input into the REDCap system. This recommendation underscores the importance of maintaining high standards in data management processes to enhance the credibility and validity of research outcomes in the field of sickle cell medical research.

Keywords: *Redcap, Quality of Data, Sickle Cell Medical Research Program.*

Introduction

Medical research is an integral part of advancing healthcare and improving patient outcomes. Efficient data management and accurate information capture are critical components of successful medical research. Traditional methods of data collection and storage can be time-consuming, error-prone, and cumbersome. To address these challenges, Research Electronic Data Capture (REDCap) has

emerged as a popular and widely used electronic data capture (EDC) tool in medical research settings (Haried et al, 2019). Accurate and reliable data collection is essential for conducting quality medical research in Tanzania. Medical research plays a pivotal role in advancing healthcare systems and improving patient outcomes. Robust data capture and management are essential components of successful medical research (Malekia, 2017). Medical research generates vast amounts of data that must be



reliably and securely collected, managed, and shared. Traditionally, researchers have used paper-based methods or basic spreadsheet software to collect and organize study data. However, these techniques have significant limitations that can hinder the research process. Errors and inconsistencies in data transcription reduce data quality. Tracking and managing multiple paper records for large studies is cumbersome and time-consuming. Sharing data with collaborators is difficult and risks data loss or breach of sensitive information (Kianers, 2021). To mitigate the challenges above, Research Electronic Data Capture (REDCap) was adopted to support data capture and management for research studies. One aspect of the problem is assessing whether REDCap improves data quality and accuracy in medical research. Accurate and reliable data are crucial for drawing valid conclusions and making informed decisions in healthcare. REDCap offers features such as data validation rules, skip patterns, and branching logic that can help minimize errors during data entry (Mare, 2022).

However, it is necessary to investigate whether these features effectively enhance data quality and reduce the likelihood of errors. Another aspect of the problem is examining whether REDCap improves efficiency in medical research. REDCap aims to streamline data collection processes by automating tasks such as data entry, data cleaning, and report generation. However, it is important to evaluate whether REDCap indeed improves efficiency in practice and whether any potential drawbacks or limitations exist. In that regard, this study sought to assess the influence of REDCap in improving the quality of data in sickle cell medical research program in Tanzania since most of the studies conducted in Tanzania did not sufficiently focus on REDCap particularly in Sickle Cell Program. For example, Ndume (2013) assessed improving data collection and integration of electronic healthcare records and not effectiveness of REDCap in improving medical research. Meanwhile Malekia (2017) assessed active health research monitoring in Tanzania and not effectiveness of REDCap in improving medical research.

Literature Review

Theoretical Literature Review

Data Management Theory

According to Emmam (2018) data management theory refers to the principles, concepts, and practices that guide the effective and efficient handling of data within an organization. It encompasses various aspects such as data governance, data quality, data integration, data security, and data lifecycle management. The goal of data management theory is to ensure that data is accurate, consistent, accessible, and secure throughout its lifecycle. One key aspect of data management theory is data governance. Data governance includes defining roles and responsibilities for data management, establishing data standards and guidelines, and implementing processes for data quality assurance. Through implementing effective data governance practices, organizations can ensure that their data is reliable and trustworthy. Another important concept in data management theory is data integration. This refers to the process of combining data from different sources into a unified view. Data management theory plays a crucial role in improving medical research through the use of Research Electronic Data Capture (REDCap) systems. REDCap is a secure, web-based application designed to support data capture for research studies. It provides researchers with a robust platform for designing data collection instruments, managing data entry and validation, and facilitating data analysis. One of the key aspects of data management theory that is relevant to REDCap is data quality.

Empirical Literature Review

Emam (2009) focused on the use of electronic data capture tools in clinical trials. The primary objective was to estimate the proportion of phase II/III/IV Canadian clinical trials that used an EDC system in 2016 and 2017. Findings indicated that flexibility of REDCap's form builder enables researchers to design forms that align with the specific objectives of their study and capture all the necessary data elements. REDCap incorporates built-in data validation

features that help ensure the accuracy and integrity of collected data. Researchers can define validation rules within the system to enforce data quality standards and prevent entry errors. For example, REDCap can validate the format of entered values (e.g., date or numeric ranges), check for missing or inconsistent data, and provide real-time feedback to users during data entry. These validation mechanisms reduce the likelihood of errors and improve the overall quality of collected data in sickle cell medical research studies.

The study by Eman (2018) holds water in this study since it entails how REDCap improves the research program in the sense that it enables researchers to design forms that align with the specific objectives of their study and capture all the necessary data elements. The similar case is observed in the study by Mare (2022) that a significant advantage of using REDCap in sickle cell medical research is its ability to facilitate remote data capture. With the increasing popularity of telemedicine and remote patient monitoring, REDCap provides a secure platform for patients to enter their own data from home or other remote locations. This not only improves convenience for participants but also reduces the burden on healthcare providers and researchers who would otherwise need to collect data through in-person visits. REDCap offers robust security measures to protect sensitive patient information.

On the other hand, the study by Harris (2019) unveiled that REDCap has a user-friendly interface that is intuitive and easy to use, which can help researchers to enter data more accurately. The interface often includes built-in data entry guidelines, which can help to reduce data entry errors. REDCap provides robust data security measures, such as user authentication and role-based access controls, which help to protect the integrity of the data. This ensures that only authorized personnel have access to the data, reducing the risk of data tampering or unauthorized changes. REDCap allows for real-

time data monitoring and auditing, enabling researchers to identify any discrepancies or irregularities in the data promptly. This feature helps to ensure that any errors or issues are addressed quickly, thereby improving the overall data accuracy. REDCap facilitates efficient data management by providing tools for data export, data importing, and data tracking. This helps researchers to organize and manage their data effectively, reducing the likelihood of data errors or loss. REDCap enables researchers to implement quality control measures by providing features for data quality checks and validation checks. These measures help to maintain the accuracy and integrity of the data throughout the research process.

Materials and Methods

The study was conducted in Dar es Salaam at Muhimbili University of Health and Allied Sciences' (Sickle Cell Program) SCP 5 satellite clinics, which included MNH-Mloganzila, Amana, Mwananyamala, MNH Upanga, and Aghakan (in special collaboration with SCP). These sites were chosen as they are the hubs for the Sickle cell research centres where REDCap was applied hence provide sources for relevant information for the research. The study adopted a descriptive research design that applied a mixed method approach which enabled the research to assess the contribution of REDCap in improving medical research in Tanzania. The study employed a mixed-methods approach that incorporates components of quantitative and qualitative research. Mixed method approach allowed the incorporation of both qualitative and quantitative techniques hence provide the researcher with a more complete picture than a solitary quantitative or qualitative study (Creswell, 2014). A total of 52 out of a population of 60 SCP staff from respective clinics and main office (Table 1), participated in the research. The sample size conformed to Yamane (1967) formula.

Table 1. Sample Size Distribution

S/n	Categorisation	Population	Sample size	Percentage of sample size %
1	Senior staff	5	4	7.7
2	Operational staff	55	48	92.3
	Total	60	52	100.0

Source: Field Data, 2023

The study deployed simple random sampling technique to select 48 operational staff and purposive sampling technique to select 4 senior staff. The selection of simple random sampling technique was based on the fact that unlike other sampling methods, such as stratified sampling or cluster sampling, simple random sampling does not require the researcher to have information about the population or to divide the population into subgroups. This made it a cost-effective and efficient method for selecting participants, especially when working with large populations. Simple random sampling is less susceptible to bias than other sampling methods. Because every member of the population has an equal chance of being selected, there is no opportunity for the researcher to intentionally or unintentionally select participants based on certain criteria. This helped to ensure that the sample is representative of the population and that the results are generalizable to the larger population. For the case of purposive sampling technique, this technique was used to select 5 senior staff since not every information could be extracted from the operational staff, hence purposive sampling technique was used. 5 respondents as senior staff were selected based on the fact that they had adequate information related to the problem under investigation Both questionnaire and interview were used to gather data from the respondents while data were analyzed using descriptive and inferential analysis.

Results

Socio-Demographic Characteristics

This section presents and discusses three socio-demographic components of respondents which are sex, age, and level of education as depicted in Table 2.

Table 2. Social Demographic Characteristics of Respondents

		N (%)
Gender	Female	25 (51.92%)
	Male	27 (48.08%)
Age group	Under 25	1(1.92%)
	25-34	26(50.00%)
	35-44	19(36.54%)
	45-54	6(11.54%)
Level of education	High school or equivalent	4
	Bachelor's degree	24
	Master's degree	19
	Doctorate or professional degree	5

Source: Field Data, 2023

Sex

Sex of the respondents as presented in Table 2 the findings shows that the distribution of sex and gender indicates that both females and males were well-represented in the study, with slightly more males (51.92%) than females (48.08%). Understanding the demographic balance is essential for tailoring research strategies and interventions, including within the MUHAS-Sickle Cell Program.

Age

Age of the respondents is an important demographic factor in understanding the investigation of the particular study. This provides a picture of the energy levels of the workforce of the respondents. Age in a study picks up the life cycle effect and is a measure of potential labour force experience. Results in Table 2 indicate that, 1.92% of the participants were under 25 years old (1 individual), while the majority fell within the age range of 25-34 years, constituting 50.00% of the sample (26 individuals). Additionally, 36.54% were between the ages of 35-44 (19 individuals), and 11.54%

were aged 45-54 (6 individuals). Findings tally to United Republic of Tanzania report of (2018) which reported that the optimal age of students to join for bachelor degree studies ranges from 21-24 years. It also signifies that most of graduates in Tanzania have young age required for labour force.

Level of Education and Professionalism

Findings presented in Table 2 indicate that the majority of the distribution of educational levels was documented. Four individuals had completed high school or an equivalent level of education, twenty-four individuals had attained a Bachelor's degree, nineteen individuals had achieved a Master's degree, and five individuals had acquired a Doctorate or professional degree. This data offers a glimpse into the educational diversity within the surveyed population, demonstrating varying degrees of academic accomplishment. The number of individuals at each educational level reflects the spectrum of educational qualifications within the dataset, showcasing the educational foundation and expertise of the participants.

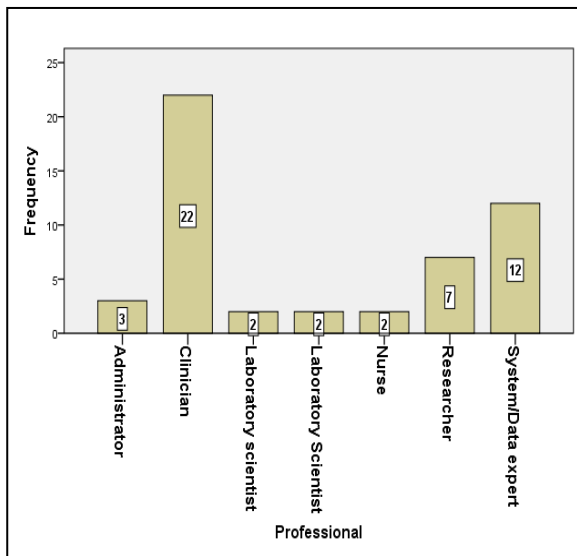


Figure 1. Professionalism
Source: Field Data, 2023

Findings presented in Figure 1 indicate that the distribution of professionals across various roles, including administrators, clinicians, laboratory scientists, nurses, researchers, and data experts,

in the context of research implies a rich diversity of expertise and perspectives contributing to a comprehensive research approach. Collaboration among these professionals fosters an interdisciplinary research environment, where clinicians provide practical insights, laboratory scientists offer technical expertise, and data experts contribute statistical analysis, ensuring a holistic understanding of research objectives and methodologies. Incorporating a patient-centric approach facilitated by clinicians and nurses ensures research designs align with patient needs, ultimately enhancing the relevance and impact of the research on healthcare practices. The overall number of professionals was 50 rather than 52 since two individuals did not fill out their professional information.

Influence of REDCap Data Quality on Improving Sickle Cell Medical Research Program

The study sought to examine the effectiveness of REDCap in improving the quality of data in sickle cell medical research program. The findings are presented in figures.

Influence of REDCap on Collection of Necessary Variables and Information

Respondents were asked whether REDCap has facilitated the collection of all necessary variables and information for sickle cell medical research. In that regard, Figure 2 indicates summary of the study findings:

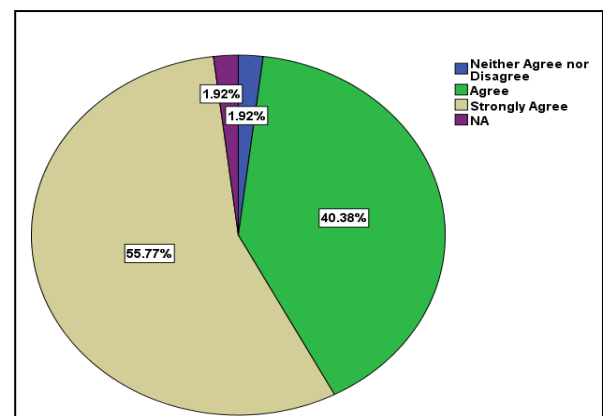


Figure 2. Collection of Necessary Variables and Information
Source: Field Data, 2023

The data illustrates a strong consensus among participants regarding the facilitation of comprehensive data collection by REDCap for sickle cell medical research. Specifically, a significant majority, 55.77%, strongly agreed that REDCap has effectively facilitated the collection of all necessary variables and essential information for research purposes. Additionally, a substantial proportion, 40.38%, expressed agreement with this statement, further emphasizing the platform's efficiency in gathering the required data. Only a minimal percentage, 1.92%, disagreed, suggesting a rare dissenting perspective on the platform's effectiveness in enabling comprehensive data collection for research related to sickle cell disease.

Influence of Redcap on the Completeness of Data

Respondents were asked whether the use of REDCap has improved the completeness of data collected in sickle cell medical research. The study findings are therefore presented in Figure 3.

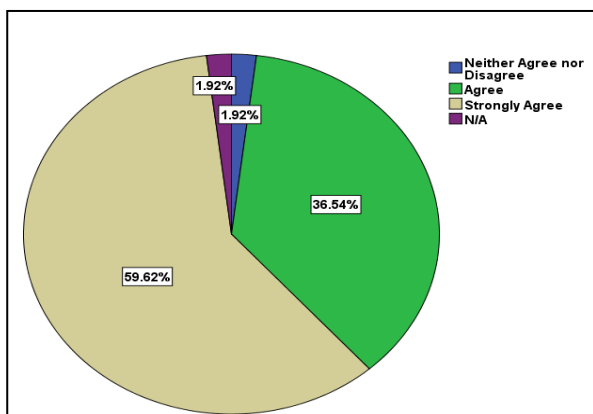


Figure 3. Completeness of Data Collected
Source: Field Data, 2023

Findings from Figure 43 revealed that the data demonstrates a prevailing sentiment regarding the role of REDCap in enhancing the completeness of data collected for sickle cell medical research. A significant majority, 59.62%, held a positive view, affirming that the utilization of REDCap has indeed contributed to

improving the completeness of collected data. Furthermore, a substantial proportion, 36.54%, shared a similar perspective, reinforcing the notion that REDCap has had a positive impact on data completeness. A small percentage, 1.92%, remained neutral, indicating a minor segment of respondents who neither agreed nor disagreed with the statement.

Influence of REDCap on Data Consistency

In this category of question respondents were asked whether the use of REDCap has improved the consistency of data collected in sickle cell medical research. The study findings are therefore presented in Figure 4.

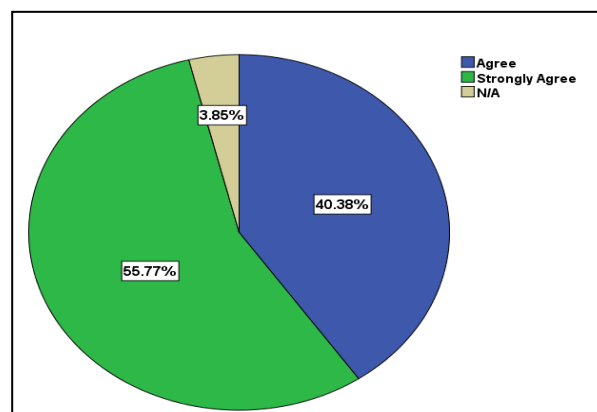


Figure 4. Consistency of Data Collected
Source: Field Data, 2023

Findings from Figure 4 show that data showcases a strong consensus among participants regarding the impact of REDCap on enhancing data consistency in sickle cell medical research. A significant majority, comprising 55.77%, strongly agreed that utilizing REDCap has substantially improved the consistency of the collected data. Additionally, a substantial proportion, 40.38%, expressed agreement with this assertion, further highlighting the platform's positive influence on data consistency. A minor percentage, 3.85%, assumed a neutral stance, indicating a small segment of respondents who neither strongly agreed nor disagreed.

Influence of REDCap on Data Accuracy

In this category of question, respondents were asked whether the use of REDCap has improved

the accuracy of data collected in sickle cell medical research. In that regard, Figure 5 indicates summary of the study findings as obtained from the field: - A substantial majority, comprising 61.54%, strongly agreed that the use of REDCap has improved the accuracy of data collected in sickle cell medical research while a significant proportion, 36.54%, expressed agreement with this assertion, underscoring the fact that use of REDCap has improved the accuracy of data collected in sickle cell medical research.

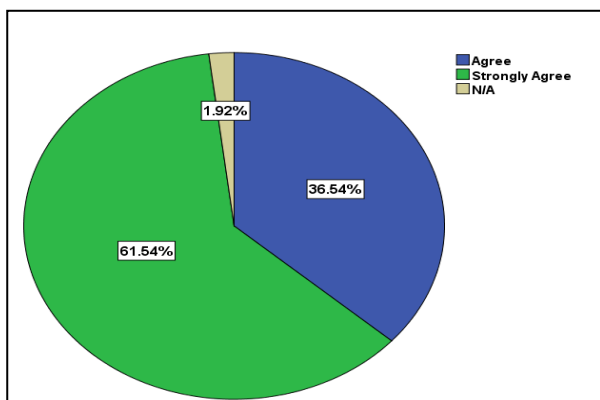


Figure 5. Accuracy of Data Collected
Source: Field Data, 2023

However, a small percentage, 1.92%, assumed a neutral stance, indicating a minor segment of respondents who neither strongly agreed nor disagreed.

Discussion

Respondents were asked whether REDCap has facilitated the collection of all necessary variables and information for sickle cell medical research. Overall, these findings highlight the pivotal role of REDCap in streamlining data collection processes and ensuring the acquisition of crucial variables for robust sickle cell medical research. This implies that REDCap allows researcher to create customizable data collection forms tailored to their specific research needs. These forms can be designed to capture a wide range of variables and information relevant to sickle cell medical research, including patient

demographics, medical history, laboratory results, treatment interventions, and outcomes. In that regard REDCap facilitates the collection of all necessary variables and information for sickle cell medical research through its customizable data collection forms, data validation and quality control features, data security and privacy measures, data monitoring and reporting capabilities, as well as its collaborative environment for efficient teamwork. This is also in in line with Emam (2009) who claimed that the flexibility of REDCap's form builder enables researchers to design forms that align with the specific objectives of their study and capture all the necessary data elements. REDCap incorporates built-in data validation features that help ensure the accuracy and integrity of collected data. Researchers can define validation rules within the system to enforce data quality standards and prevent entry errors. For example, REDCap can validate the format of entered values (e.g., date or numeric ranges), check for missing or inconsistent data, and provide real-time feedback to users during data entry. These validation mechanisms reduce the likelihood of errors and improve the overall quality of collected data in sickle cell medical research studies.

On the fact that the use of REDCap has improved the completeness of data collected in sickle cell medical research. Overall, these results underscore the beneficial effect of REDCap in bolstering the comprehensiveness and overall quality of data collected in the domain of sickle cell medical research. This indicates that one of the primary reasons why the use of REDCap has improved the completeness of data collected in sickle cell medical research is its user-friendly interface. The platform provides researchers with an intuitive and easy-to-navigate interface, allowing them to efficiently enter and manage data. This user-friendly design reduces the likelihood of errors and omissions during data entry, ensuring that all relevant information is captured accurately.

In the same trail the findings indicate that the use of Research Electronic Data Capture (REDCap) has significantly improved the completeness of

data collected in sickle cell medical research. Its user-friendly interface, built-in validation checks, real-time data entry capabilities, support for longitudinal studies, and advanced data management features all contribute to enhancing the quality and accuracy of collected data. REDCap also incorporates built-in data validation checks, which further enhance data completeness. These checks can be customized based on the specific requirements of the study, ensuring that researchers adhere to predefined rules and guidelines when entering data. For example, if a certain field requires a numerical value within a specific range, REDCap can automatically flag any entries that fall outside of this range, prompting researchers to review and correct the data. Generally, the use of Research Electronic Data Capture (REDCap) has significantly improved the completeness of data collected in sickle cell medical research. Its user-friendly interface, built-in validation checks, real-time data entry capabilities, support for longitudinal studies, and advanced data management features all contribute to enhancing the quality and accuracy of collected data.

Also, the use of REDCap has improved the consistency of data collected in sickle cell medical research. Overall, these findings emphasize the crucial role of REDCap in ensuring a consistent and reliable dataset in the realm of sickle cell medical research. Thus, the use of REDCap has significantly improved the consistency of data collected in sickle cell medical research. Its standardized approach to data collection, data validation features, remote data capture capabilities, and robust security measures all contribute to enhancing the quality and reliability of the collected data.

The study findings are connected to the study by Mare (2022) that through utilizing REDCap, researchers can streamline their research processes, reduce errors, and ultimately advance our understanding and treatment of sickle cell disease. Also, one of the key advantages of using REDCap in sickle cell medical research is its ability to provide a standardized and structured approach to data collection. The platform allows researchers to create electronic case report forms (eCRFs) that are tailored to their specific study

requirements. These eCRFs can include various types of data fields, such as text, numeric, date, and multiple-choice options, ensuring that data is collected consistently across different study sites and researchers

In the same trail, the study indicated that the use of REDCap has improved the accuracy of data collected in sickle cell medical research. This entails that the use of REDCap in sickle cell medical research has streamlined data collection, enhanced data accuracy, and improved overall research efficiency, leading to more reliable and robust research findings in the field of sickle cell disease. In addition, REDCap provides standardized data collection templates, which ensure that data is collected uniformly across different sites and researchers. This reduces the chances of errors that may arise due to inconsistent data collection methods. Also, REDCap offers features for data validation, including range checks and data type checks, which help to identify any inconsistencies or errors in the data being entered. This feature helps to ensure that the data collected is accurate and consistent.

The study findings are supported by data management theory. Data management theory plays a crucial role in improving medical research through the use of Research Electronic Data Capture (REDCap) systems. REDCap is a secure, web-based application designed to support data capture for research studies. It provides researchers with a robust platform for designing data collection instruments, managing data entry and validation, and facilitating data analysis. One of the key aspects of data management theory that is relevant to REDCap is data quality. Data quality refers to the accuracy, completeness, consistency, and reliability of the data collected. In medical research, high-quality data is essential for drawing valid conclusions and making informed decisions. Data management theory provides guidelines and best practices for ensuring data quality throughout the research process.

Generally, these findings draw the conclusion that REDCap incorporates various features and functionalities that align with data management

theory to enhance data quality. For instance, it allows researchers to design customized data entry forms with built-in validation rules. These rules can help prevent errors during data entry by enforcing specific formats or ranges for certain variables. Through adhering to data management principles, such as ensuring proper documentation and standardization of variables, REDCap promotes the collection of high-quality data. Another aspect of data management theory that is relevant to REDCap is data security and privacy. Medical research often involves sensitive patient information, and it is crucial to protect this data from unauthorized access or breaches.

Conclusion

The study examined the influence of redcap in improving the quality of data in sickle cell medical research program. The study demonstrates that using REDCap's specialized features for clinical/medical research data collection leads to more complete, accurate, and standardized data. Through facilitating better data quality, REDCap was found to enable more robust analysis and higher quality research on sickle cell disease. The authors recommend adopting REDCap as a best practice for any medical research program, especially for complex diseases like sickle cell that require large multifaceted data sets. This study provides clear evidence that REDCap improves data quality for sickle cell medical research across key metrics. The findings support the broader adoption of electronic data capture systems like REDCap to enhance the reliability and usefulness of clinical research data.

Recommendations

The control of data quality is of utmost importance in any data management system, and this holds true for REDCap as well. REDCap, which stands for Research Electronic Data Capture, is a secure web application designed for data collection and management in research studies. To ensure that the data input into REDCap is correct and dependable, it is crucial

to implement stringent quality control procedures. One way to achieve this is by implementing validation rules during data entry. Validation rules are predefined checks that ensure the accuracy and consistency of the entered data. These rules can be set up to validate various aspects of the data, such as format, range, or logical relationships between different fields. Through enforcing these rules, errors and inconsistencies can be minimized or even eliminated at the point of data entry.

Another important aspect of maintaining data quality in REDCap is ongoing training programs. These programs should be designed to cater to both new users who are just starting to use REDCap and current users who may need refresher courses or advanced training. Through providing comprehensive training on how to properly collect, enter, and manage data in REDCap, users can improve their data management abilities and reduce the likelihood of errors.

Furthermore, promoting a culture of data integrity is essential for maintaining high-quality data in REDCap. This involves increasing awareness among all stakeholders about the importance of correct and consistent data. Researchers, study coordinators, data managers, and other individuals involved in the research process should understand the impact that inaccurate or inconsistent data can have on research outcomes. Through emphasizing the significance of data integrity and fostering a culture that values accurate and reliable data, stakeholders will be more motivated to adhere to quality control procedures and ensure the integrity of the collected data. Therefore, ensuring the control of data quality in REDCap requires implementing stringent quality control procedures, providing ongoing training programs for users, and promoting a culture of data integrity among all stakeholders. By prioritizing these aspects, researchers can enhance the reliability and validity of the data collected in REDCap, ultimately leading to more robust research outcomes.

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