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## Reply to iManage: A Novel Self-management App for Sickle Cell Disease

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### Keywords

sickle cell; adolescents and young adults; mHealth; smartphone; app; self-management

To the Editor:

We would like to thank Dr. Badawy for his letter[1] regarding our study "Development and Evaluation of iManage: A Self-Management App Co-Designed by Adolescents with Sickle Cell Disease." [2] The letter highlights important technology challenges encountered in the development and evaluation of mobile health (mHealth) applications (apps) like iManage. We concur that the operating system is an important consideration particularly since adolescents and young adults (AYA) living with sickle cell disease (SCD) may have less access to iOS based devices (iPhone/iPad). Thus, the iManage app was developed for use on the iOS and Android platforms. We also agree that data privacy and security issues are paramount to mHealth. To ensure that the data collected via iManage is confidential, accurate and reliable, [3] data is automatically encrypted. Data access is limited to the app developer, the data owner (LC) and study staff. All data are backed up daily and stored on a server in our institution's main datacenter, which is monitored 24 hours per day. Study staff review user data by logging into an administrative portal also housed on a server in the datacenter. To limit disclosure of protected health information, AYA receive unique login credentials, and sign a data security and privacy contract prior to using iManage. Different mHealth functionality/features give rise to distinct risks to information security and privacy which need to be addressed individually. [4] For example, any medical information entered

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into the patient profile section of iManage is kept private and cannot be viewed by other users. iManage users can view each other's progress on self-management goals; however, AYA see only the status of another AYA's self-management goal (complete, not complete) not the content. Additionally, the iManage messaging and reminder functions may be viewed by others in the user's environment (i.e., family, friends) but are general and do not include user names. AYA use iManage to track daily pain and mood symptoms over time, but this data is private and cannot be viewed by other iManage users. Currently, psychology staff monitors AYA symptoms because staff has weekly contact with all users since they are participating in a larger self-management intervention study. Our research team is exploring AYA and provider preferences for handling any concerning symptoms reported in the app (i.e. patient or provider prompt if high pain severity or low mood are reported). The next step will be to evaluate the feasibility and impact of these prompts on AYA self-management and health outcomes.

### Abbreviations:

<b>AYA</b>	adolescents and young adults
<b>SCD</b>	sickle cell disease
<b>mHealth</b>	mobile health technology
<b>App</b>	application

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