

mobilizing the participant voice

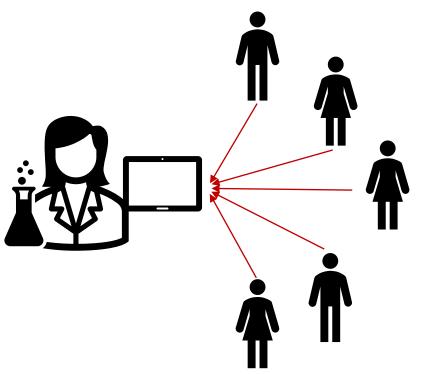
Dionne Grant and Jess Eidenmuller

Vanderbilt Institute for Clinical and Translational Research (VICTR)

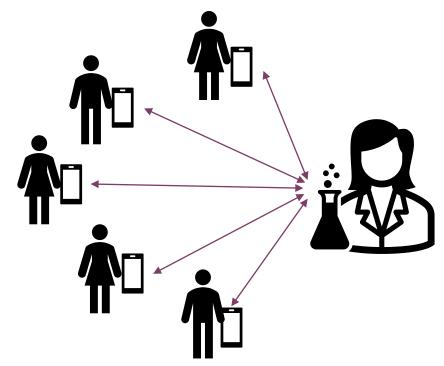
https://projectmycap.org mycap@vumc.org

REDCap Mobile Solutions – REDCap Mobile App & MyCap

The REDCap Mobile App and MyCap are two mobile applications that help extend REDCap's functionality to capture patient-reported outcomes.



REDCap Mobile App is used by **data collectors** (REDCap users)



MyCap is an app used by **study participants** (Family members)





The Basics: What is MyCap?

A tool for researchers – a customizable participant-facing mobile application freely available to capture patient reported outcomes based a REDCap project.

A tool for participants – a centralized study 'home' for information and actions that facilitates continuous participant engagement and participant retention.



The Participant's "Research Home" away from clinic

Participants can:

- Submit data and complete research activities
- Send / receive messages (e.g., ask study questions; receive reminders for upcoming events, appointments, visits)
- Locate study & contact information
- Access links to web-based information and resources



Key MyCap Features

Multiple Participants per Device



Multiple Studies per Participant



Customized Daily Task Reminder

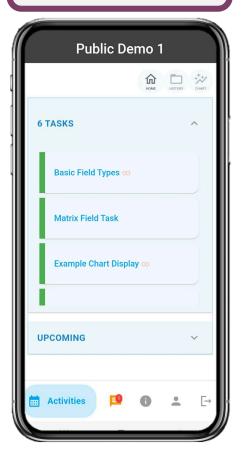


Customized Task Scheduling

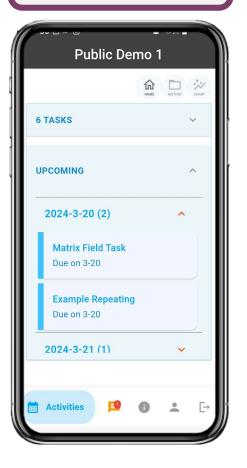
| Set the Task Schedule: | |
|-----------------------------|--|
| Schedule it how many times? | One Time |
| | ○ Infinite |
| | Repeating |
| | C Repeats Daily ✓ |
| | ○ Fixed |
| | On Day(s): 1,7 |
| Number of days to delay | 0 |
| End this Repeating task | Never |
| | When any of the below conditions are TRUE: |
| | After it has been completed 2 times |
| | After 0 days have elapsed |
| | At exact date: MM/DD/YYYY 31 M/D/Y |
| | |

Task Completion & Anticipation

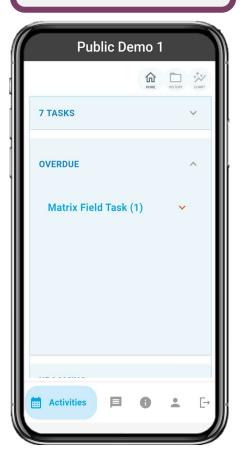
Today's Tasks



Upcoming Tasks



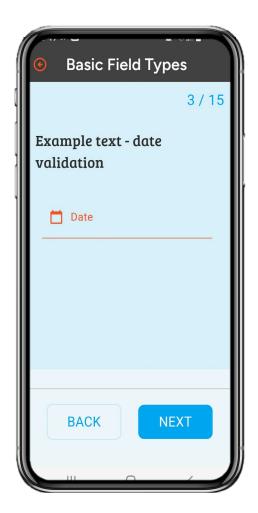
Overdue Tasks



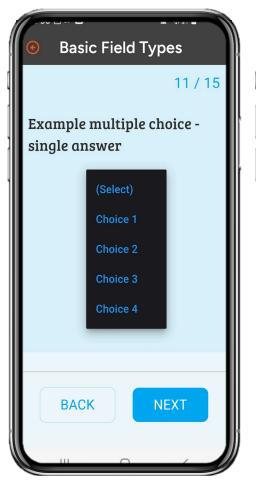
Calendar View

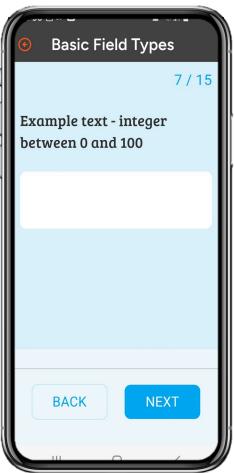


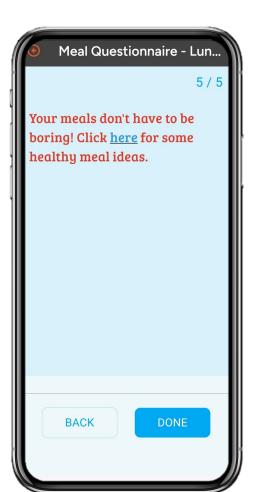
Participant Surveys











Additional Features

About Pages



Contacts Page



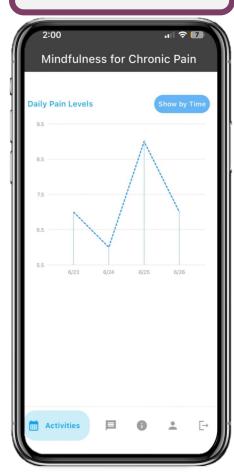
Hyperlinks to Web-Based Resources



Bi-directional Messaging

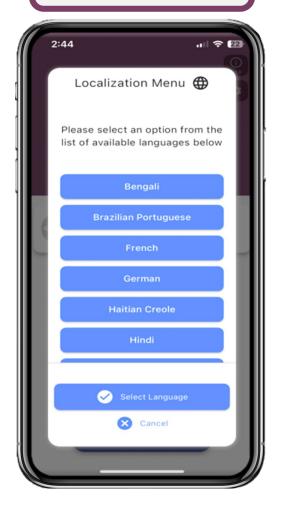


Customize Timing of 1x Daily Task Reminder



Multiple Languages

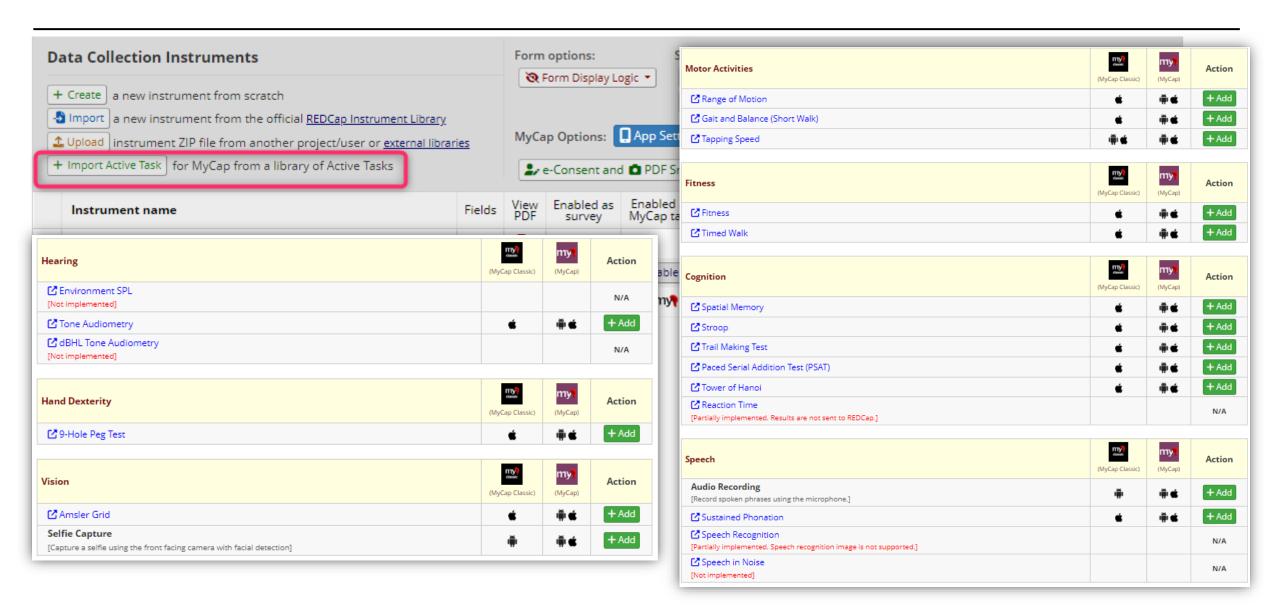
MyCap Available in 17 Languages



REDCap's Multi-Language Management



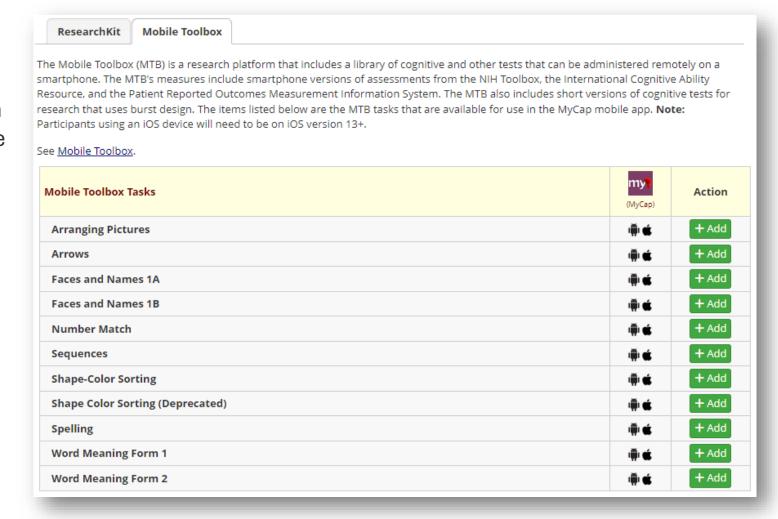
MyCap "Active Tasks"



MyCap Supports NIH's Mobile Toolbox (MTB)

- MTB is a research platform of cognitive and other tests, administered remotely on a smartphone.
- Smartphone versions of assessments from the NIH Toolbox, the International Cognitive Ability Resource, and the Patient Reported Outcomes Measurement Information System.

https://mobiletoolbox.org/

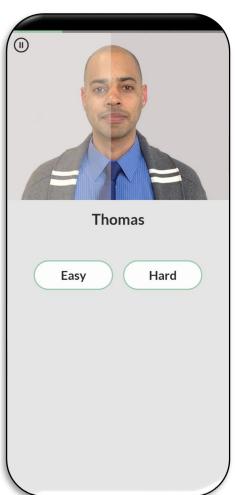


Mobile Toolbox

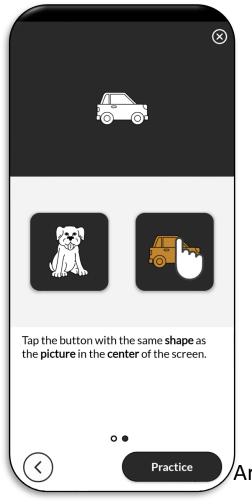
Word Meaning



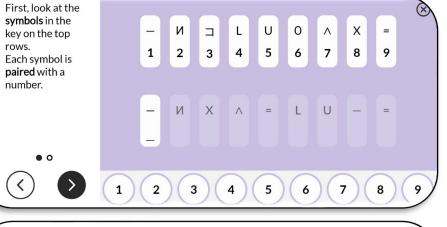




Shape Color Sorting



Number Match



Always tap the button that matches the direction of the center arrow.

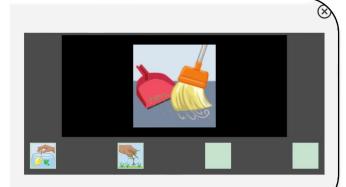


Arrows

Pictures with audio will appear on the screen in a specific order.

Notice where each picture is placed.



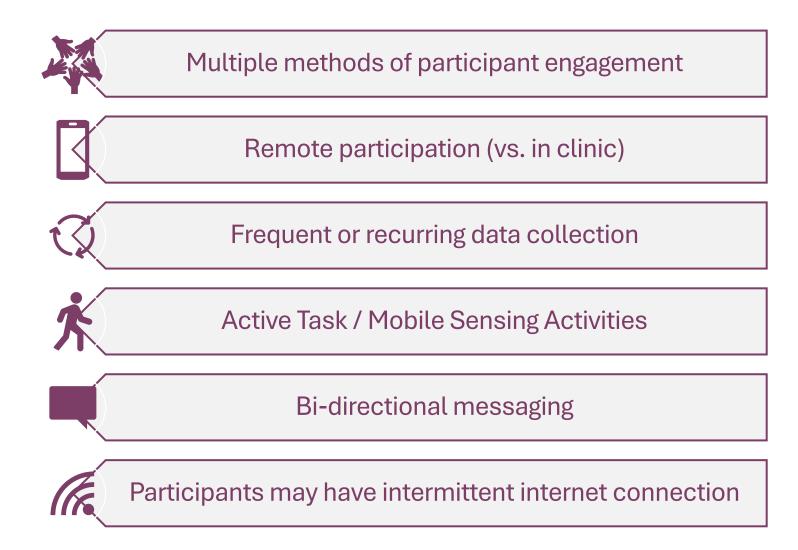


Planned Enhancements

Coming in 2025:

- Support for REDCap's Form Display Logic
 - Trigger tasks
 - Discontinue tasks
- Task-specific notifications (multiple notifications per day)

When is MyCap a Good Fit for a Study?





MyCap Utilization



MyCap Growth: January 2024-January 2025



MyCap Growth: January 2024-January 2025

Use Cases

- Evaluation of MyCap to capture PROs from women in early stages of labor
- Parkinson's Disease Identification using finger tapping task
- Remote patient monitoring/surveillance
- Assessment of Anxiety in Pediatric Patients with Multiple Sclerosis
- Medication Adherence (with adults) and postintervention symptom monitoring (w/ child caregivers)
- Post-surgery Home Exercise Intervention (activity reporting)
- Program delivery: Behavioral Intervention Tracking
- Disparities in autism spectrum disorder diagnosis with caregivers and children on the same device: Evaluation of diagnostic accuracy, psychometric properties, and family engagement

https://projectmycap.org/mycap-use-cases/

MYCAP USE CASES

Below are select MyCap use cases gathered through bibliometric searches. If you have a published or written up use case, please submit it here.

| Study Information | MyCap Utility | Audience | References |
|---|--|-----------------------------------|--------------------------|
| Evaluation of Women in Active Labor- A collaboration of five academic centers across the United States utilized MyCap to collect real-time information about individual's experiences from the onset of spontaneous labor through hospital admission for birth. | Patients track contraction frequency and duration in MyCap when symptoms of labor begin. They also record symptoms and coping methods when the latent phase of labor progresses. | Pregnant women | Click here to read more. |
| Assessment of Anxiety in Pediatric Patients with Multiple Sclerosis— The NYU Langone Multiple Sclerosis (MS) Center utilized MyCap to monitor anxiety levels of patients with MS while enrolled in an intervention that assessed the use of Attention Bias Modification Training for anxiety reduction. | Participants completed questionnaires related to their depression, anxiety, and affect on MyCap pre-intervention, weekly during the 1-month intervention, and post-intervention. | Pediatric patients | Click here to read more. |
| Remote Patient Monitoring (RPM)— The Mt. Sinai Health System utilized MyCap to monitor patients who recently suffered a stroke or were at risk for stroke to assess their need for triage and care. | Patients assessed their BP and heart rate daily and entered values into MyCap. | Adults | Click here to read more. |
| Remote Patient Monitoring (RPM)- The Mt. Sinai Health System launched the COVID-19 Precision Recovery Program in 2020, using MyCap for remote patient monitoring. | Patients logged daily symptoms and physiologic data in MyCap, which were monitored by clinical staff to identify when triage or in-person care was needed. | Adults | Click here to read more. |
| Medication Adherence- The University of Washington and Sammamish TruMedicines conducted a pilot study assessing efficacy of mobile apps in measuring or encouraging medication adherence. | Participants photographed a pill before daily consumption and answered accompanying health-related questions. | Adults | Click here to read more. |
| Covid-19 Surveillance- Vanderbilt University Medical Center conducted a COVID-19 surveillance study at a local high school and used MyCap to connect participant samples with test results. | Participants collected weekly saliva samples and completed symptom questionnaires. MyCap's barcode scanning feature linked participant sample test tubes to test results, which were pushed to participants' MyCap app. | Highschool students & teachers | Click here to read more. |
| Parkinson's Disease Identification- Weill Cornell used MyCap to identify Parkinson's Disease patients from Healthy Controls by utilizing the Tapping active task. | Participants completed the active tapping task 2x about 1 hour apart, 3 days per week, for 5 weeks on MyCap. | Adults | Click here to read more. |

Participant Feedback:

Evaluating Use of MyCap within a financial incentives study (n=268)

On what type of device did you use MyCap?

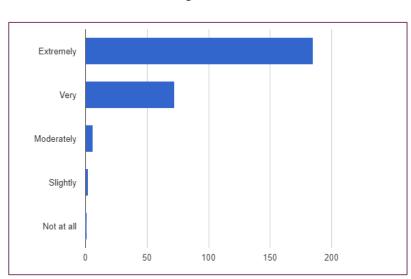
Android (50.4%) | iOS (49.6%)

Did you have any problems using MyCap?

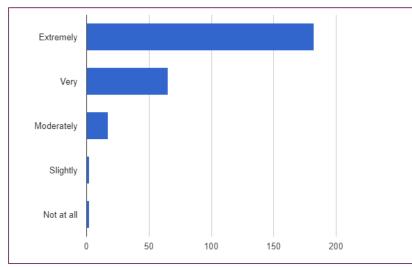
Yes (4.5%) | No (95.5%)

• Did you have any concerns about the confidentiality of the data provided in MyCap? Yes (2.2%) | No (97.8%)

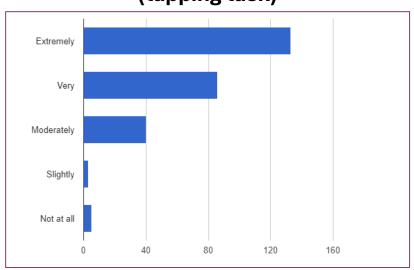
Easy to Join



Easy to Complete Tasks (surveys)



Easy to Complete Active Task (tapping task)



Meier S, Cheng A, Tischbein M, et al. Impact of financial compensation on enrollment and participation in a remote, mobile-app based research study. *Journal of Clinical and Translational Science*. 2024;8(1):e75. doi:10.1017/cts.2024.515

Participant Demographics

| Characteristic | Responded to invitation | Said yes + downloaded MyCap | Declined participation |
|----------------------|----------------------------|-----------------------------------|---------------------------|
| | n = 492 | n = 286 | <i>n</i> = 50 |
| Age | N (%) | N (%) | N (%) |
| 18–29 | 118 (23.9) | 71 (25) | 6 (12) |
| 30–49 | 186 (37.8) | 127 (44.7) | 13 (26) |
| 50–64 | 104 (21.1) | 52 (18.3) | 13 (26) |
| 65–74 | 56 (11.3) | 25 (8.8) | 10 (20) |
| 75 and older | 21 (4.2) | 8 (2.8) | 8 (16) |
| Prefer not to answer | 1 (<1) | 1 (<1) | 0 (0) |





Race/Ethnicity

- American Indian/Alaska Native n=6
- Asian or Asian American n=26
- Black, African American, African **n=67**
- Hispanic, Latino, Spanish **n=63**
- Middle Eastern, North Africa n=3
- Native Hawaiian, other Pacific Islander n=0
- White, Caucasian **n=153**

Meier S, Cheng A, Tischbein M, et al. Impact of financial compensation on enrollment and participation in a remote, mobile-app based research study. *Journal of Clinical and Translational Science*. 2024;8(1):e75. doi:10.1017/cts.2024.515

Additional Feedback:

Ease of Use:

Participants, including the older adult cohort (55+) described MyCap as, "very user friendly and accessible". - Dr. Branche: Covid-19 vaccine trial

Users told the study team that they found the app to be "very easy to use". – Elise McGlashan: Assessment of Anti-depressants on Circadian Clock- Turner Institute for Brain and Mental Health)

Reduced Staff Burden:

"It (MyCap) saved countless man hours which would have been spent making weekly phone calls to subjects to document ILI symptoms. It also allowed us to have more accurate detection of ILI symptoms so that we could bring participants in for illness visits to screen for influenza infection and understand mechanisms of immune escape from vaccination." – Dr. Branche: Covid-19 vaccine trial

Effective Remote Coordination:

"MyCap was crucial in allowing us to conduct that work in a fully remote environment, which allowed us to include participants from all across the U.S." – Dr. Meier: FACCT Study

"We are all over the country and MyCap allowed us to work together really well." – Dr. Phillippi: Collecting Real-Time Patient Reported Outcomes During Latent Labor

Data Completeness:

"We haven't had a single day of a missed sleep diary, the patients find it super easy, and the flexibility in scheduling some items to occur every day relative to install, while having another schedule for weekly or fortnightly items relative to their lab assessments is great." –Elise McGlashan: Assessment of Anti-depressants on Circadian Clock (Turner Institute for Brain and Mental Health)

Key Considerations

Pre-requisites:

- Will participants have or be given a mobile device (phone, tablet)?
- Will participants have internet access?
- What version of REDCap is used by the institution? (>13.10.0 is recommended)

Considerations:

- How frequently are participants being asked to complete data?
- What types of data are you hoping to capture remotely?
- Will you need to support non-English-speaking participants? If so, what languages?
- Do you have web-based materials (participant brochures) or websites related to the trial or disease being studied to share with participants?

MyCap Resources

1. MyCap Promo Video:https://www.youtube.com/watch?v=HTddoQlp8nk&t=47s

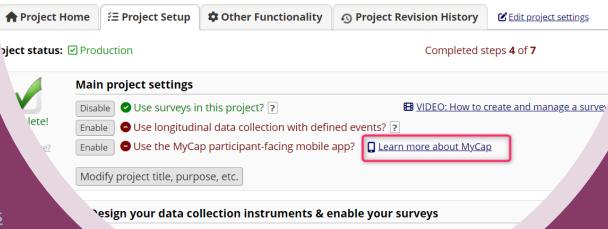
2. Email us: MyCap@vumc.org

3. From our website: https://projectmycap.org/

- 1. Check out our use cases
- 2. Read the FAQs
- 3. Browse our end-user resources
- 4. Find Demos
- 3. Sign up for our newsletter
- 4. Read the MyCap Marker Paper: MyCap Marker Paper
- 5. Demo a MyCap project by scanning the QR code below:



>> Submit the survey >> Click the MyCap link >> Demo MyCap



'it fields on your data collection instruments (survey and forms). This may be dorner (online method) or by uploading a Data Dictionary (offline method). 'seed as surveys in the Online Designer. Quick links: Download Dictionary



my Watch some short videos on how to use MyCap in a project:

- El Configure MyCap Tasks
- App Design
- MyCap Participant Management

 $\ensuremath{\square}$ Take a test drive: View the MyCap app through the eyes of a participant.

Join a demo project using the MyCap mobile app

MyCap is a participant-facing me.

Android) used for data collection and the acof active tasks (activities performed by participant device sensors under semi-controlled conditions). All acoin the MyCap app are automatically sent back to the REDCap.

MyCap is a no-code solution for research teams conducting longitudinally-designed projects or projects with frequent participant contact. MyCap also facilitates participant engagement and retention by providing quick access to project staff and two-w communications (e.g., messaging and announcements) within the app. MyCap is available on any iOS device (iOS v11.0+) and any Android device (Android v8.0+).

as soon as internet connection is available (i.e., it can also be use

 For more information about MyCap, check out the MyCap website, publication, resources, and a list of MyCap use cases

Prefer a detailed guide of instructions? Read the MyCap Help document

for offline participant data collection).

Participants can join your project on the MyCap mobile app using a QR code or hyperlink that is unique to their record in your REDCap project. A participant's record must already exist in the REDCap project in order for them to get a QR code or hyperlink.

The methods below will provide you with template language and directions for onboarding participants to your project. To obtain an individual participant's QR code or hyperlink after their record has been created in the project, see the MyCap Participant Management > MyCap Participant List. This project has been converted to the new MyCap app.

