

Capturing Prescription Diet Adherence for Patients with GSDIa: A MyCap Use Case

Vaishali Belamkar, BA¹, Riya G. Naik, MS¹, Julieta Bonvin Sallago, MD, MS^{1,2}, Jason Houle¹, and Carolyn M. Macica, PhD.^{1,2}

¹Connecticut Children's Research Institute, Hartford, CT, ²University of Connecticut School of Medicine, Farmington CT

Background

Glycogen Storage Disease Type Ia (GSDIa) is a rare disease that affects the metabolism and storage of glycogen. Management of GSDIa involves **adherence to strict dietary and uncooked cornstarch prescriptions** and monitoring of blood glucose levels to avoid hypoglycemia, a common complication in GSDIa patients. There are currently **no methods to reliably measure dietary adherence** for patients with GSDIa.

To address this gap, a **GSDIa diet adherence survey** was created and built as a MyCap task.

Adherence Survey Parameters

During a **two-year natural history study**, participants will complete **quarterly (8)** prescription adherence surveys.

- Must be deployed at a **different interval** each quarter.
- Must **NOT be visible to participants** under “Upcoming Tasks” and “Calendar” in MyCap to reduce biased adherence responses.
- Must **notify participant** when an adherence task is due.
- Must be deployed on the same day as quarterly self-report surveys separate from the adherence survey.

Over the last 3 days, did you take all the cornstarch doses as prescribed?

Yes

No

Adherence Survey MyCap Task

- **Separate events** for each quarterly adherence survey.
- Adherence Surveys instrument set as **MyCap Task**.

Y1 Q1 Adherence MyCap	Y1 Q2 Adherence MyCap	Y1 Q3 Adherence MyCap	Y1 Q4 Adherence MyCap	Y2 Q1 Adherence MyCap	Y2 Q2 Adherence MyCap	Y2 Q3 Adherence MyCap	Y2 Q4 Adherence MyCap
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Set the Task Schedule:

Relative to which date task should be scheduled?

- ☐ Install Date
- ☒ Baseline Date

MyCap task deployment relative to a **Baseline Date** (date of participant's enrollment).

Schedule it how many times?

- ☐ One Time
- ☒ Infinite
- ☐ Repeating

Schedule as “**Infinite**”. Ensures adherence survey **does not show in Upcoming Tasks or in Calendar**. Does not provide participant notification that task is due.

Repeats

- ☐ Fixed

On Day(s):

Number of days to delay was **randomly selected** for all 8 tasks by the PI prior to the start of data collection. All adherence tasks intervals are converted to number of days to delay relative to baseline

Number of days to delay

9

End this Infinite task

- ☐ Never

☒ When any of the below conditions are TRUE:

☒ After it has been completed 1 times

☐ After days have elapsed

☐ At exact date: MM-DD-YYYY M-D-Y

End this infinite task after the task is completed '1' time to ensure the participant may only complete the adherence survey once per quarter.

- Research staff must **schedule secure MyCap messages** relative to the number of days to delay for each quarter.
- Adherence **survey date instrument** created based on number of days to delay and participant's baseline date to streamline message scheduling process.
@CALCDATE([mycap_enrollment_arm_1][consent_date], 9, 'd')

Quarterly Adherence and Sleep Surveys (Baseline: 07-14-2026)

Y1 Q1: 07-23-2026	Y2 Q1: 07-17-2027
Y1 Q2: 11-06-2026	Y2 Q2: 11-30-2027
Y1 Q3: 02-02-2027	Y2 Q3: 04-09-2028
Y1 Q4: 05-03-2027	Y2 Q4: 04-12-2028

Body (* must provide value) ☐ Use the Rich Text Editor

You have a task due today for the GSD natural history study!

When to send this message?

☐ Send immediately

☒ Send at exact date/time: 11-06-2026 10:00

SEND MESSAGE

Conclusions and Significance

- MyCap is a **viable option** to capture **longitudinal patient data** to inform dietary **prescription adherence** in patients with GSDIa. Future MyCap updates may consider adding a **randomized electronic diary function** to further support capturing longitudinal prescription or protocol **adherence surveys** to streamline and simplify the REDCap build for end-users.