

# Interest in EHR-Extraction Solutions

- 🌐 Is there interest in continuing to offer solutions for families and patients with ways to pull their data and share it directly with your research teams?
  - *Remains important goal. Offers oppor for family to control access to data for research. Fundamental good. Other projects underway looking at collecting data thru mobile app thru survey.*
  - *Obtaining clinical data is still important. Also exploring other options for acquiring clinical data, web-based survey integrated with pull of clinical data.*
  - *If so, would a branded / white-label experience be of interest?*
    - *Suspect would find appealing. Not sure researchers would want to be locked into single vendor.*
    - *Branding likely to help in engaging families. Families associate trust with branding.*
  - *Beyond mobile, Medfusion also offers Web (demo later this week) and API solutions – are any of these of interest?*
    - *Some families prefer one over other. See age differences. Some populations have easier access to smart phones than to computers.*
    - *Concern over Medfusion persisting the data (despite option to delete). Need to be able to reassure patients that their data won't end up any place other than PPRN to whom they sent it.*

# Value of Data Delivered

- ❁ Are the data that have been received meeting your expectations?
  - *Researchers and investigators are ecstatic.*
  - *Enthusiastic about concept, but got so little data in the end that expectations were not met.*
  - *Originally had no idea what data would receive. Data received had value, but too little to generalize from.*

# From “Interesting” to “Essential!”

- 🌐 What would make this solution / process be something that your teams could not live without?
  - *Independent Direct address needed for long term.*
  - *Want to move into FHIR-based solutions.*
  - *More automated identification of patients.*
  - *Simplify process for patients to provide data. E.g., of 59 people who signed consent, only 4 provided data.*

# If We Only Could Fix That One Thing...

- 🌐 If you could fix one thing, what would it be?
  - *Unlimited budget. Need external support to move this beyond concept stage.*

# Monday-Morning Quarterbacking

- 🌐 Knowing what you know now, how would you have adjusted planning and expectations for the pilot?
  - *Needed more extensive set of test files, especially files that represented the issues later encountered.*
  - *Would eliminate Leadership Testing from timeline because had to drop due to privacy and security concerns. Pre-release to limited set of users might have been a better approach.*
  - *Most of issues encountered couldn't have been corrected by Medfusion.*

# The Good and the Could-Be-Better

- 🌐 Having worked with Medfusion throughout this process – what went well and where could Medfusion improve?
  - *Pilot was successful and proved to everyone (including large number of skeptics) that it could work. This is fundamental to PPRN's future.*
  - *Could not have done this without Medfusion. Very appreciative.*
  - *Although understandable, Medfusion's inability to make changes that would have made the app easier to use contributed to low response.*
  - *What will Medfusion do with data that are routed to a PPRN's Direct address moving forward?*