Constructing the Evidence Base: Interim Measures, Data Management

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Q#1: How can CSA design facilitate quality research, from program inception?

Key words: *"from program inception"*!

Issues to think about and plan for from the beginning:

① Partners – roles, data and MOUs

② Privacy – embed the permissions and anticipate multiple uses

③ Confidentiality – using the data and keeping it safe

Partners, Roles and who has what Data

ASF-Mott ------$$$---------→ ASF-Mott ☺

ASF-AEDI ------Rsrch------→ ASF-AEDI ☺

FAME-BVR ------Share------→ ASF-BVR

DOE-FAME ------Match------→ DOE-FAME-AEDI-ASF-UMaine

(or, upon further reflection,

FAME-DOE + FAME-AEDI)

Privacy and Permissions

When, where and how does someone give you permission to use their data

- Best and cleanest is to specifically get their permission (☑)
    - Then, what to do with those who don't check the box…
    - And, danger of skewing research to those who opt-in
- Opt-out will also work – at least for basic info
- What permission are they providing (ie how can the info be used)?

What we learned the hard way

- "Addendum" – would it be sufficient?!
- Updates to contact info…neglected to list "research" as a potential use

Anticipate your need to access data now and in the future!

Confidentiality

What's covered
- How can you use the data you have permission to use?
- How will you keep the data safe?

Think about "grain size" of data
- All data will be de-identified – but that may not be enough, especially with some very small cohort sizes (eg 7th grade class at Minot Consolidated School)
- For us, it is county-level data that will be reported

Protocols
- For transfer of info
- For storage
- For destruction
- Who signs the confidentiality agreements

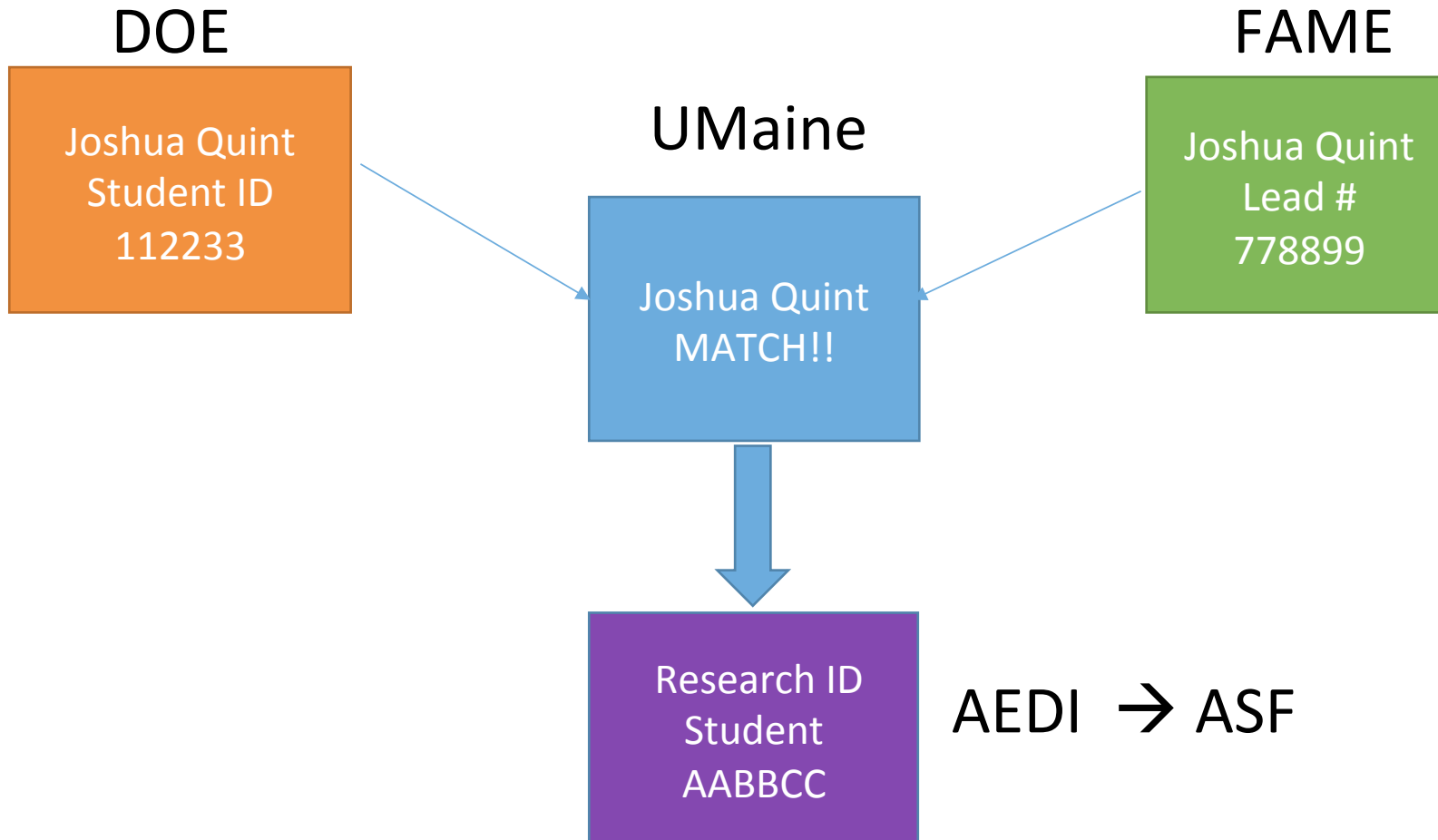# Q#2: How can CSA programs prepare for conducting research?

Have the fundamentals in place
- Partners/MOUs, Privacy/Permissions, Confidentiality

Know how you will make your match
- What fields are collected and available…and do they align?
- How is the info transmitted … can one system work with the other?
- Who touches the data?
- How confirm match accuracy ("Is this the same Joshua Quint?")
- Subsequent use
- Capture updated info
- Capture permission to continue to use!

Making the Match (Plan A)