

# Information technology solutions for reporting of registry data

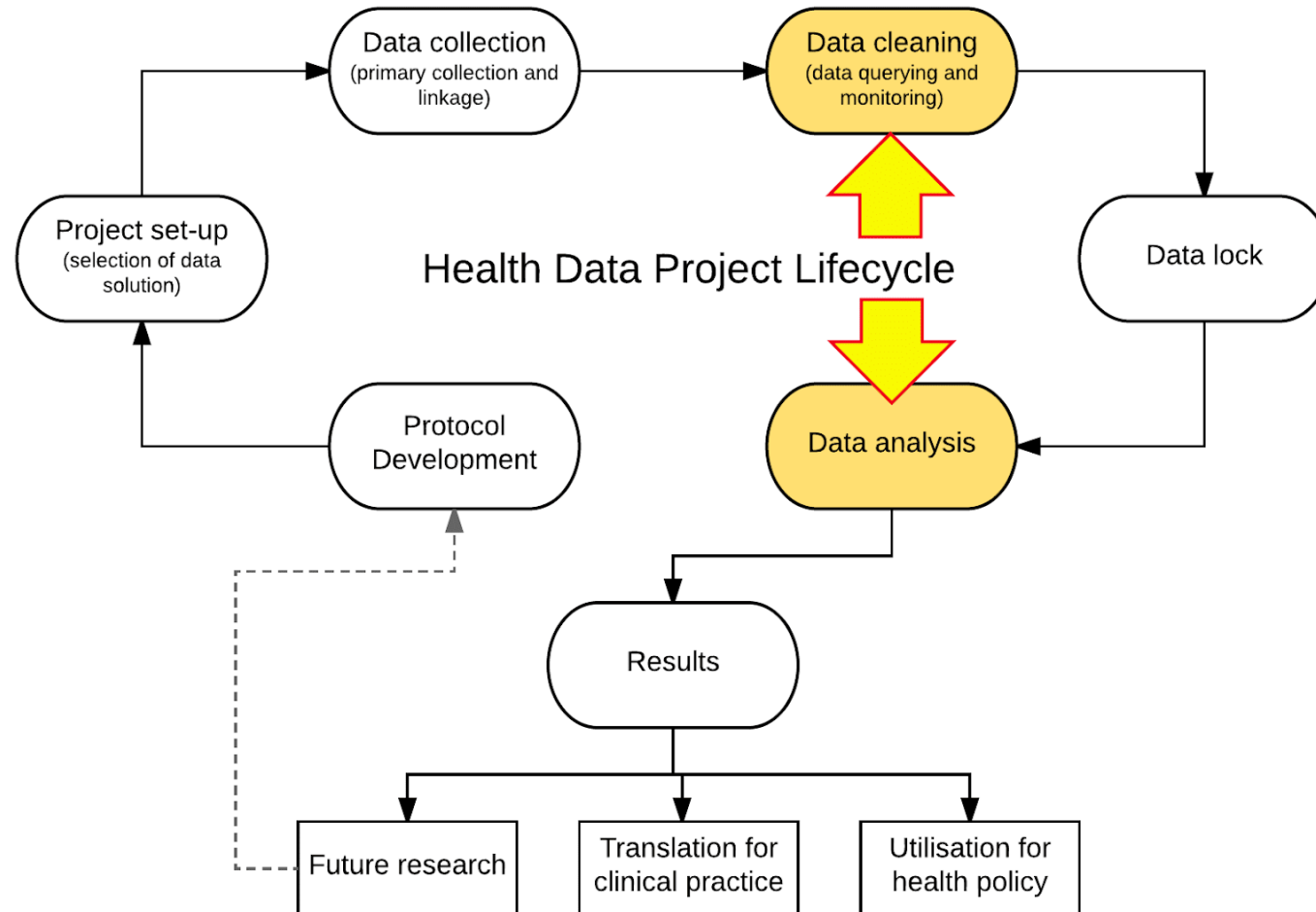
Jess Lockery



# Overview

1. Principles of operational reporting
2. Progress reporting based on workflows
3. Technology options
4. Demonstration

# Where this fits





# 1. Principles of operational reporting

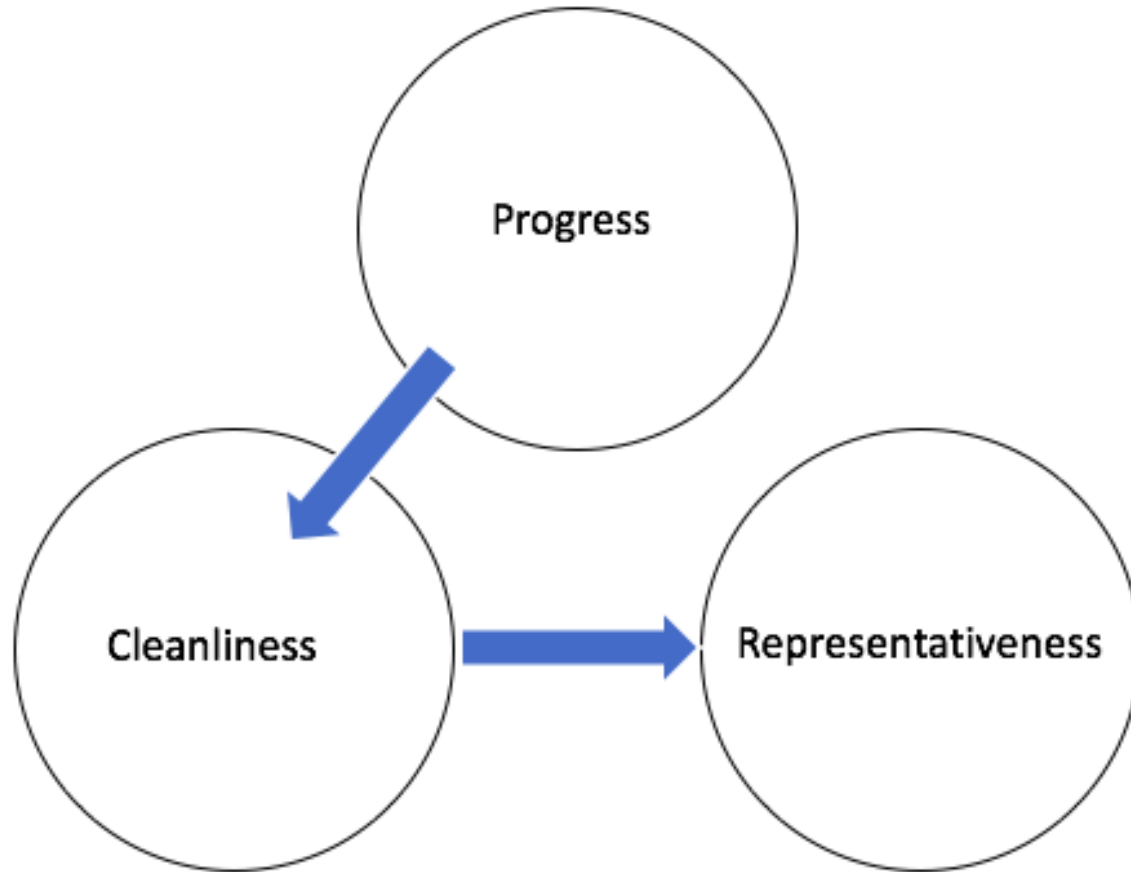
# 1. Principles of operational reporting

The trifold purpose of operational reporting is to:

- i) check that study activity is tracking against Key Performance Indicators (KPIs),
- ii) to identify system glitches to be resolved, and
- iii) to provide information for future planning.

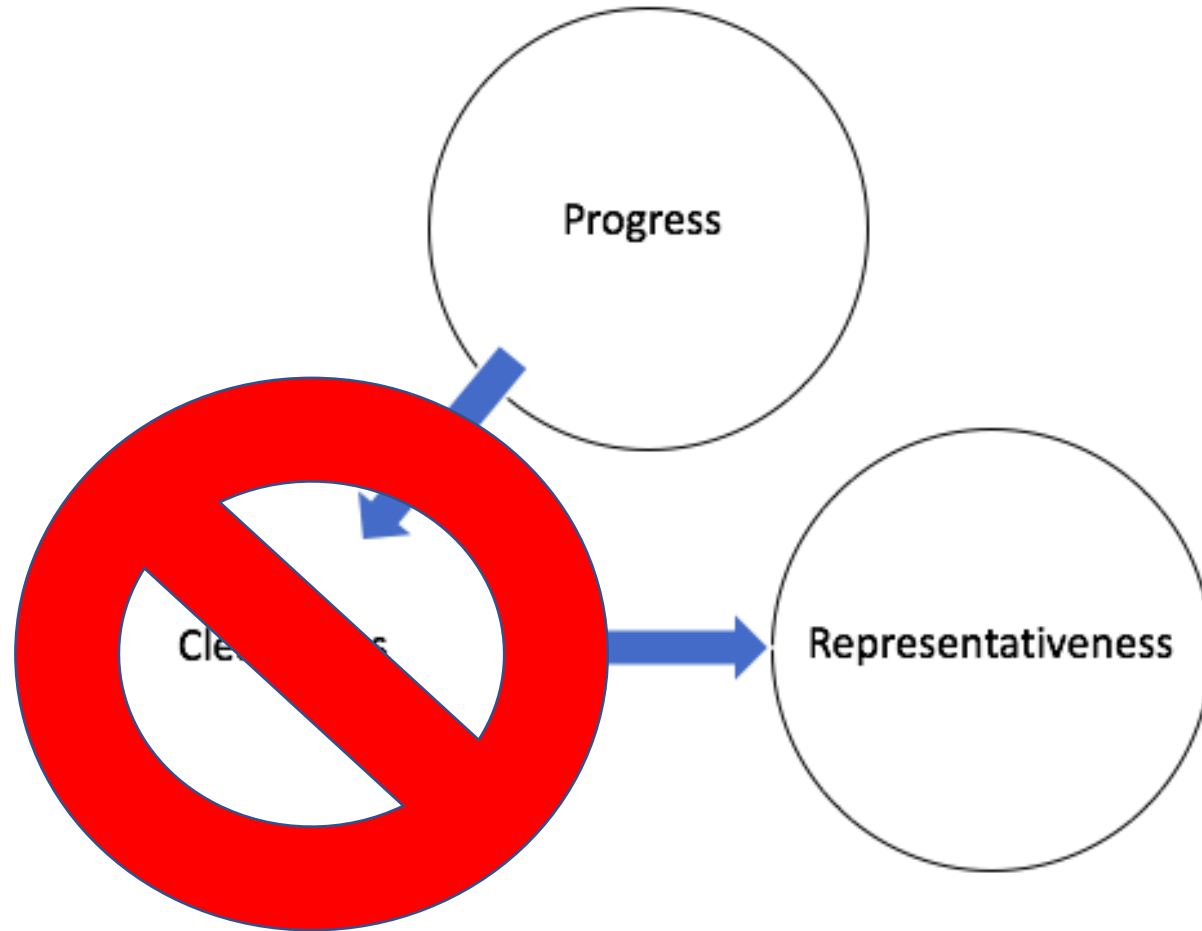
Operational reporting **is different** from outcome reporting or statistical analysis.

# 1. Principles of operational reporting

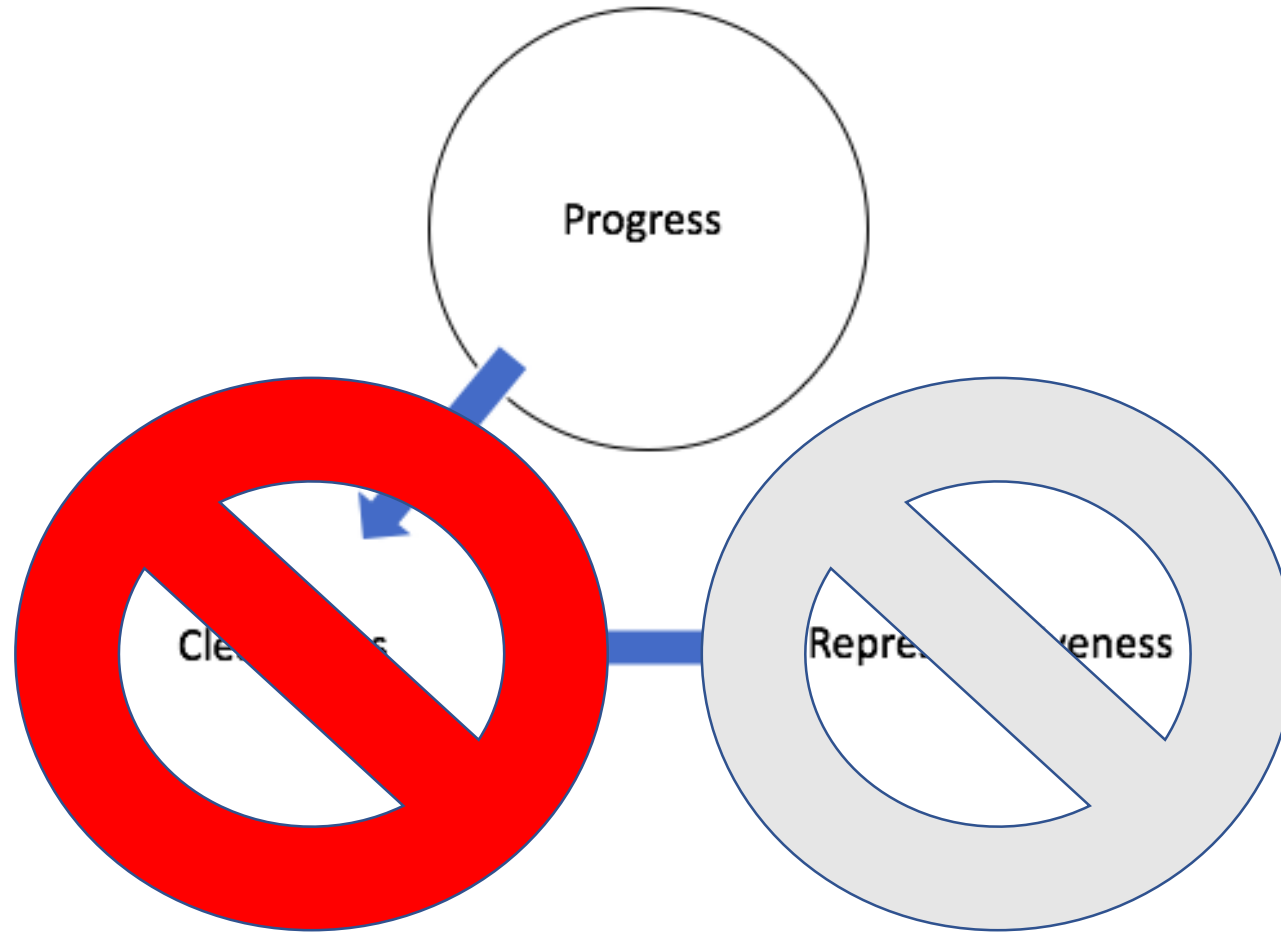




# 1. Principles of operational reporting

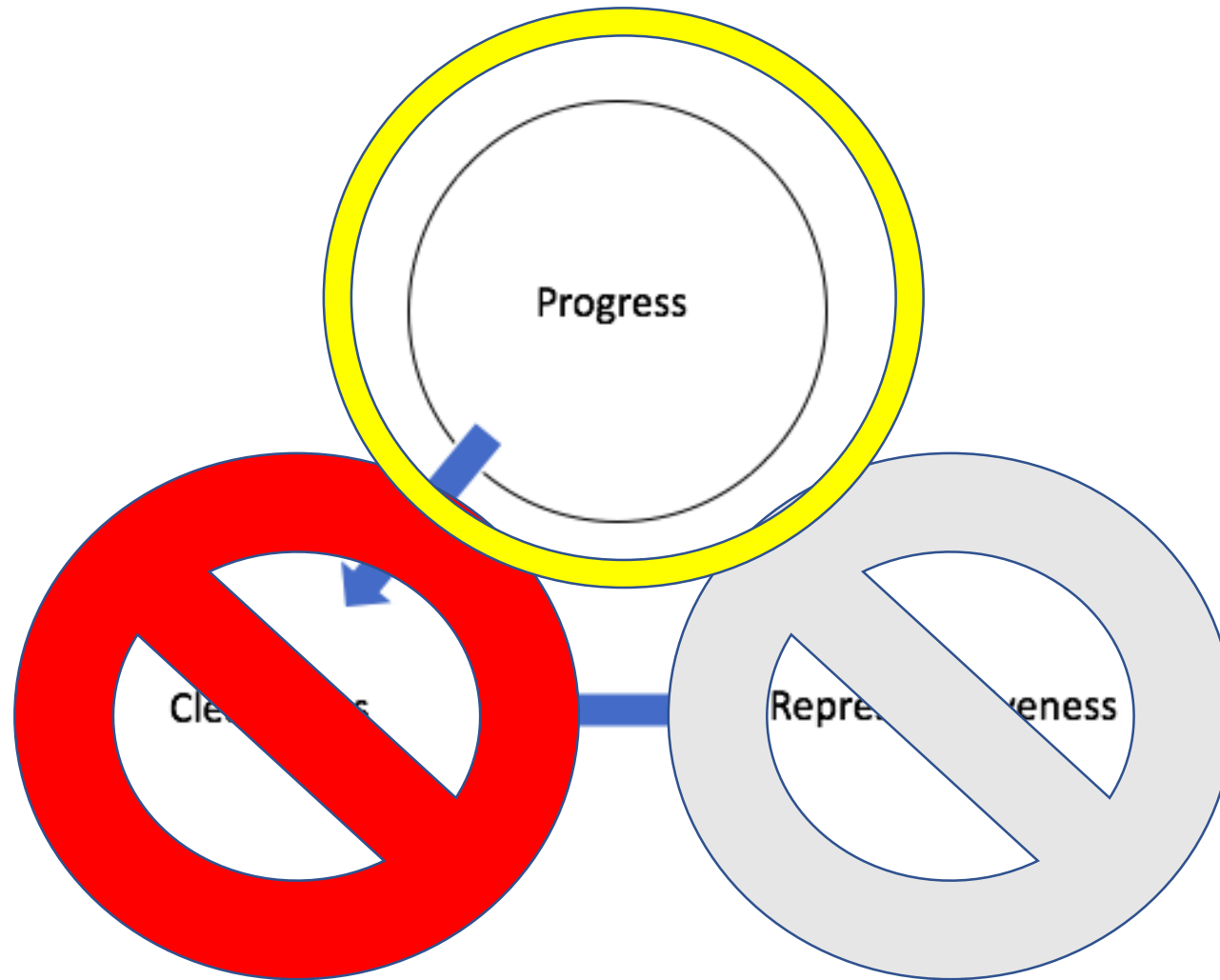


# 1. Principles of operational reporting





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## 2. Progress reporting

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What should I report?

All aspects of study activity require progress reports.



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Isn't that an enormous amount of work?!

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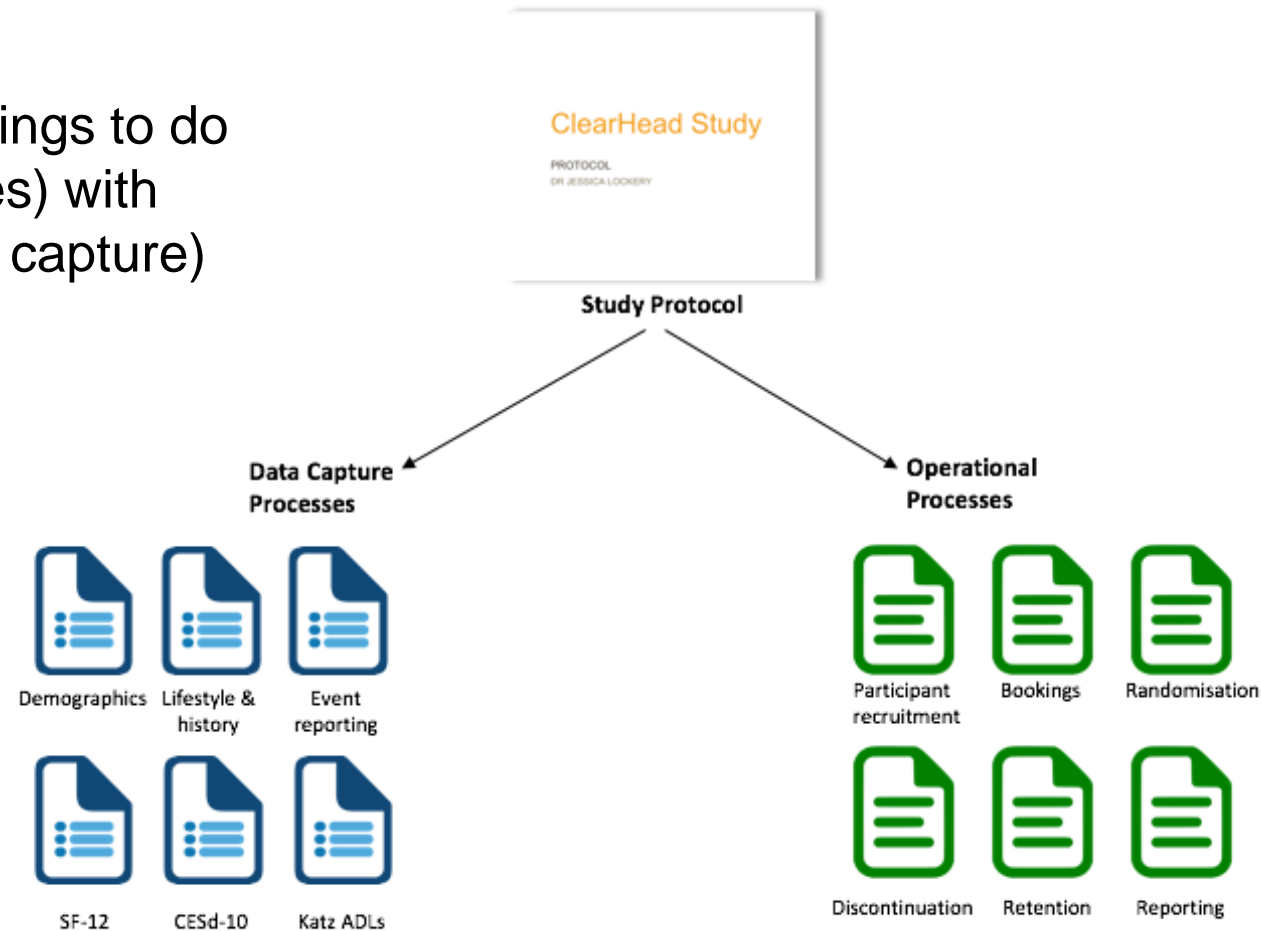
**YES!**

**Good idea to group study activity into workflows and then reports on them.**

# 2. Progress reporting

## What is a workflow?

Workflows connect things to do (operational processes) with things to record (data capture)



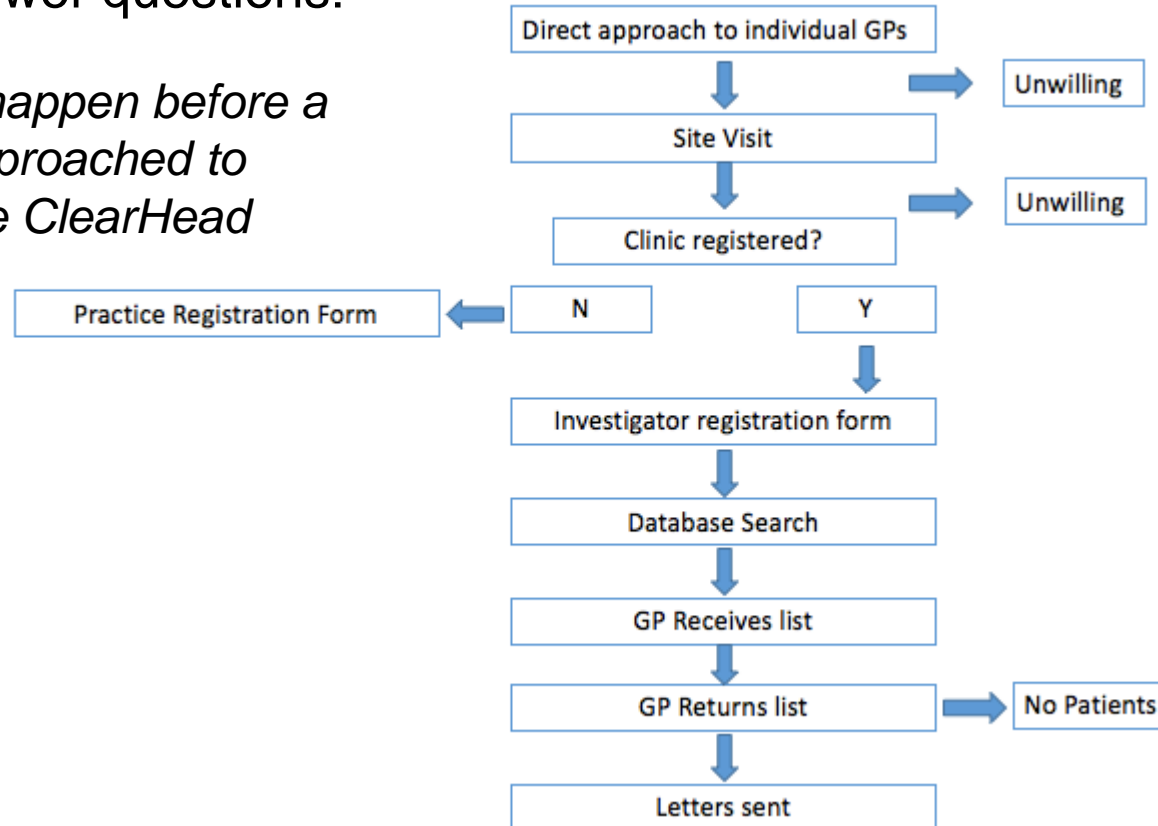


# 2. Progress reporting

## What is a workflow?

Workflows answer questions:

*What needs to happen before a participant is approached to participate in the ClearHead study?*

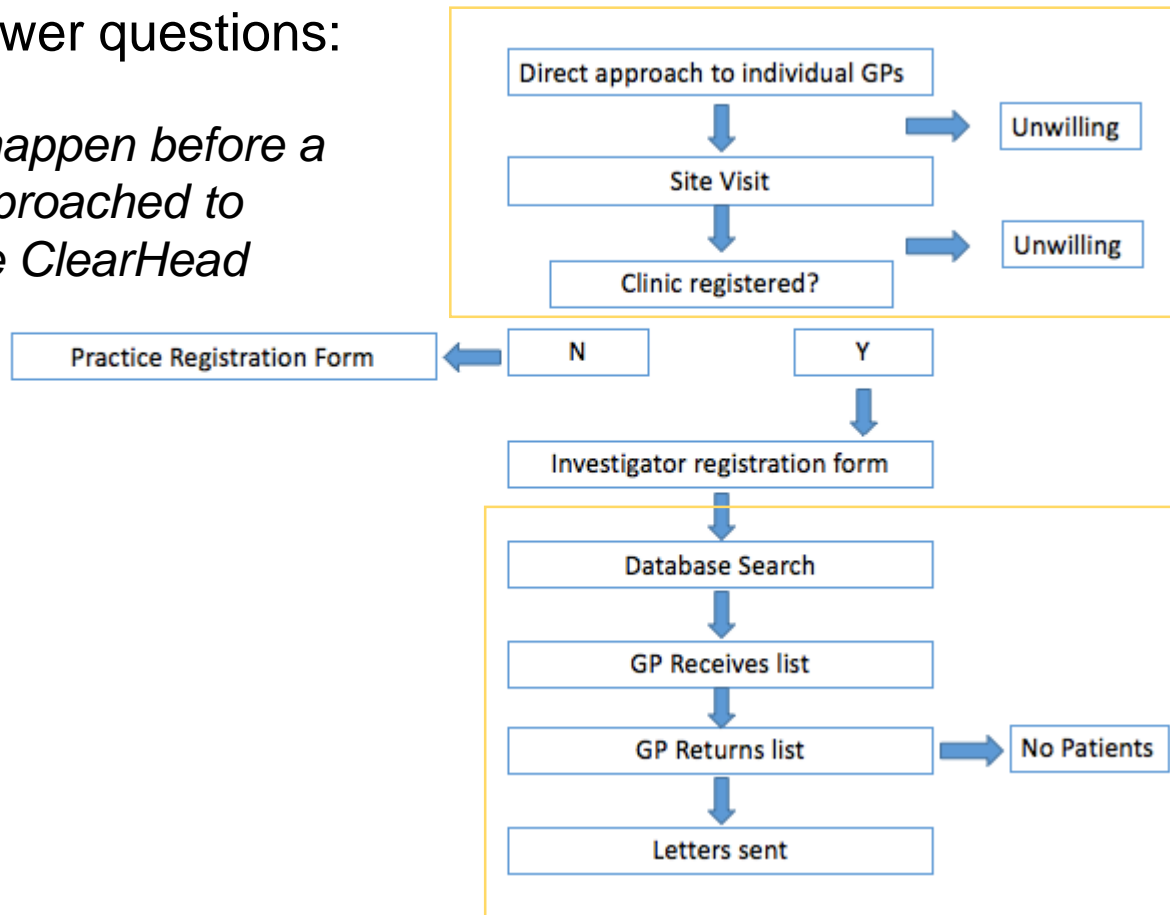


# 2. Progress reporting

What is a workflow?

Workflows answer questions:

*What needs to happen before a participant is approached to participate in the ClearHead study?*

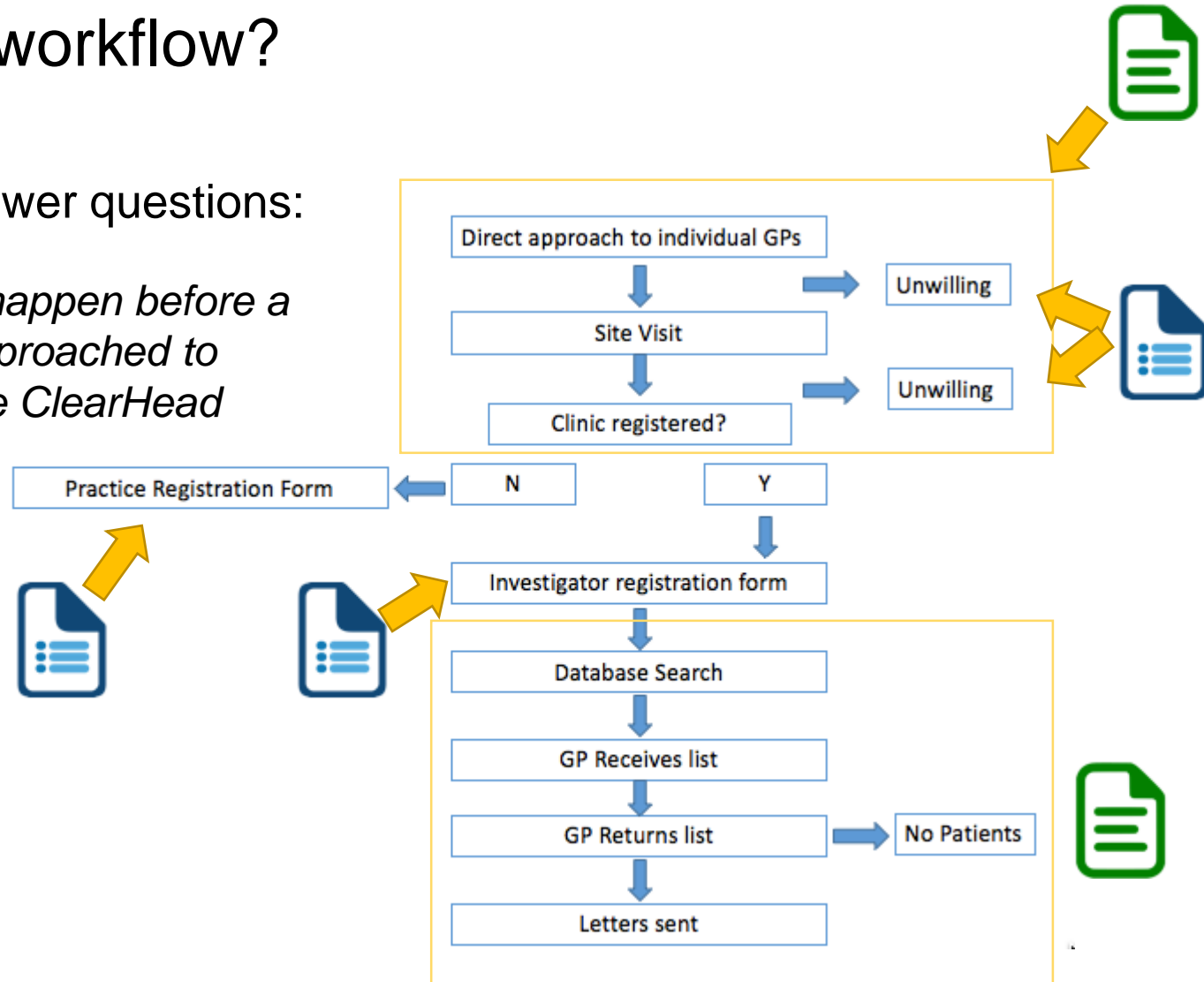


# 2. Progress reporting

What is a workflow?

Workflows answer questions:

*What needs to happen before a participant is approached to participate in the ClearHead study?*





## 2. Progress reporting

Once we understand what data needs to be recorded and what things need to be done to collect that data...

We have the information needed to design a progress report.

## 2. Progress reporting

A progress report condenses a complex workflow into a form that is more easily digestible.

Constructing a workflow and linked progress report is an **academic** task (not a technical task).

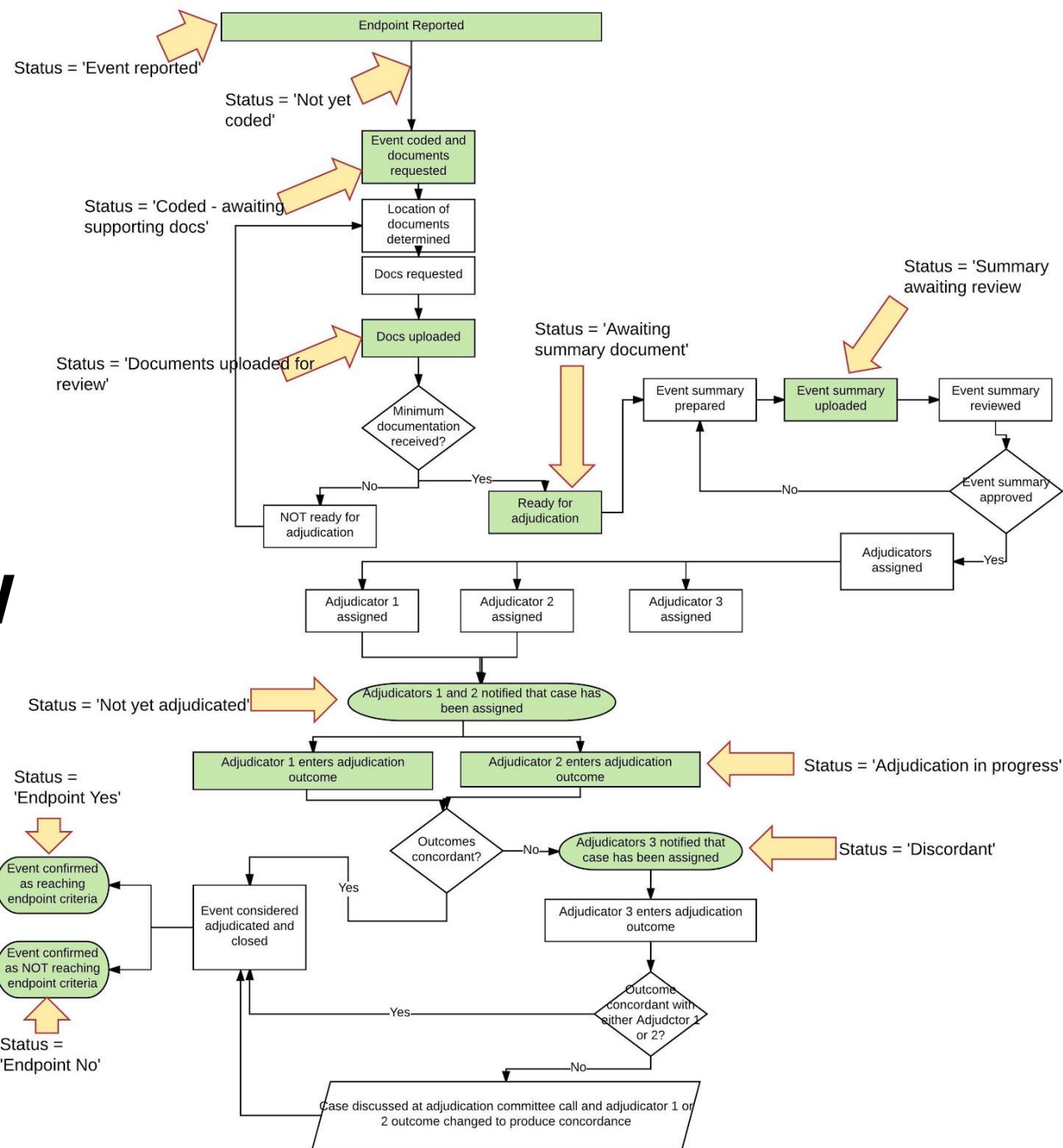
The report designer must consider what the key transitions (outcomes) are within the workflow when designing the progress report.

## 2. Progress reporting

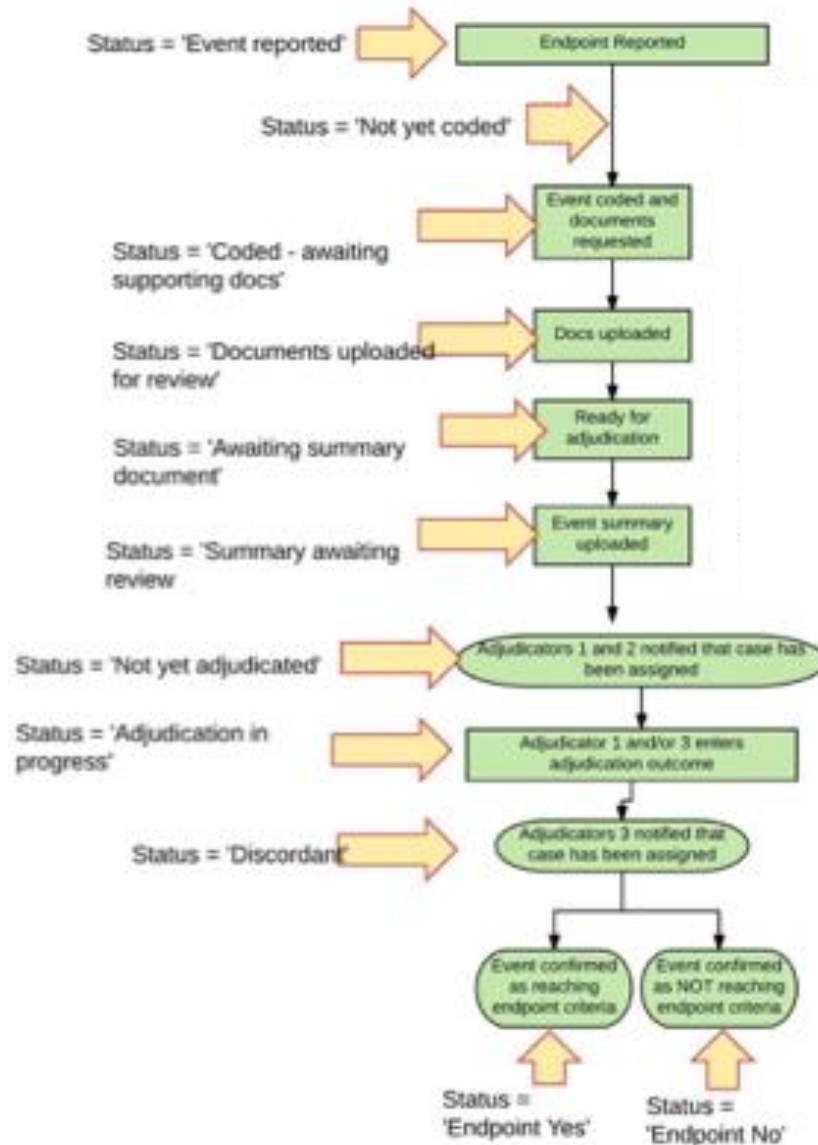
How do you turn a workflow into a report?



# Example Workflow

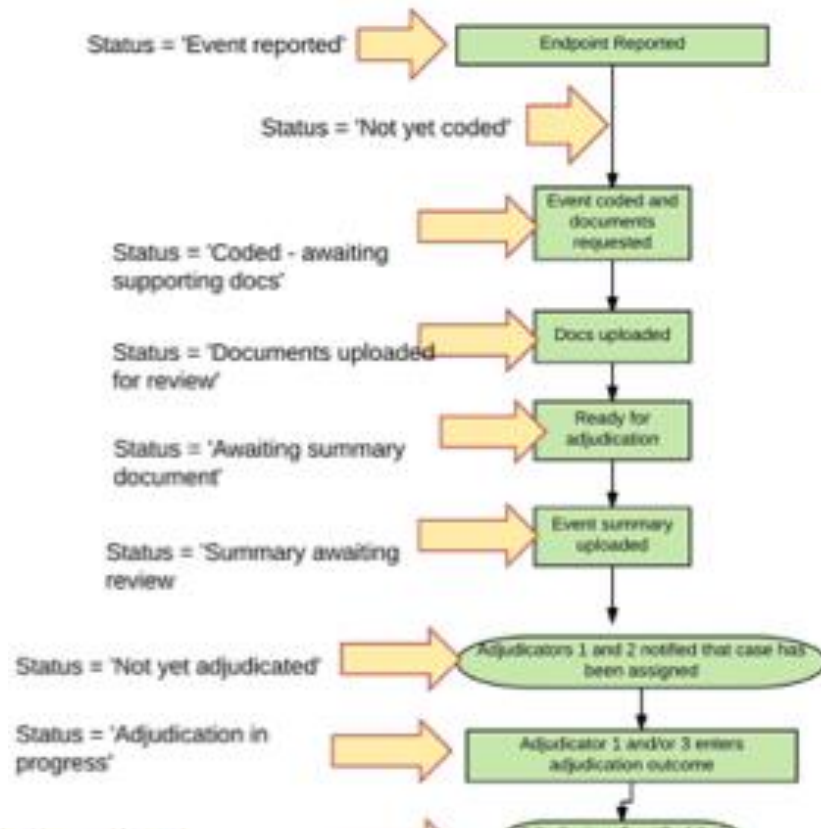


# Example Workflow





# Example Workflow



Adjudication Progress Report 1

ENDPOINT Type	Events reported	Not Yet Coded	%	Awaiting Supporting documents	%	Docs to review	%	Awaiting ETR doc	%	Awaiting Final review	%	Not yet adjudicated	%	Adjudication In progress	%	Discrepant adjudication	%	Completed Adjudications	%	ENDPOINT YES	% of adjudications	ENDPOINT NO	% of adjudications
Event 1	771	2	0%	325	42%	18	2%	16	2%	20	4%	14	2%	6	1%	5	1%	356	46%	156	44%	200	56%
Event 2	1024	0	0%	37	4%	3	0%	5	0%	30	4%	35	3%	9	1%	7	1%	889	87%	855	74%	234	26%
Event 3	906	4	0%	118	13%	5	1%	5	1%	34	4%	4	0%	11	1%	4	0%	724	80%	398	44%	326	36%
Event 4	491	24	5%	170	35%	5	1%	7	1%	22	4%	27	5%	19	4%	9	2%	208	42%	75	36%	133	64%
Event 5	1289	1	0%	21	2%	0	0%	4	0%	2	0%	13	1%	7	1%	8	1%	1233	96%	712	58%	521	42%
TOTAL	4484	31	1%	671	15%	31	1%	37	1%	126	3%	93	2%	52	1%	33	1%	3410	76%	1996	45%	1414	32%

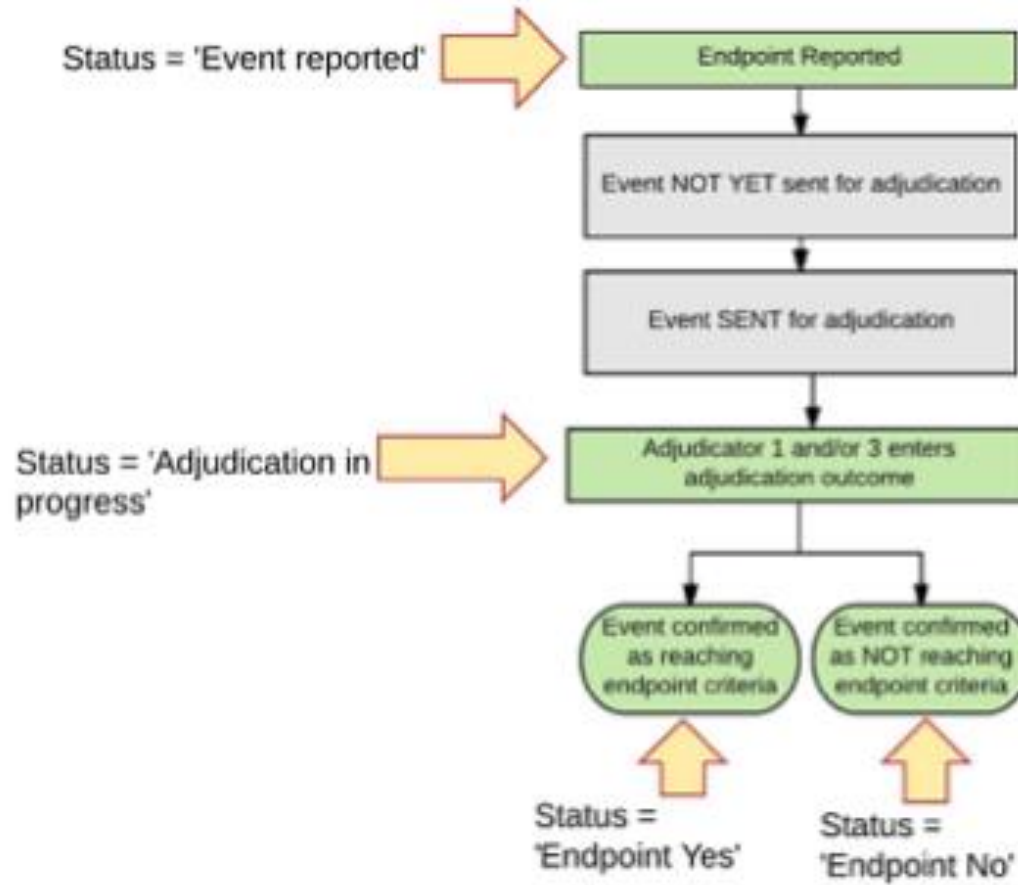




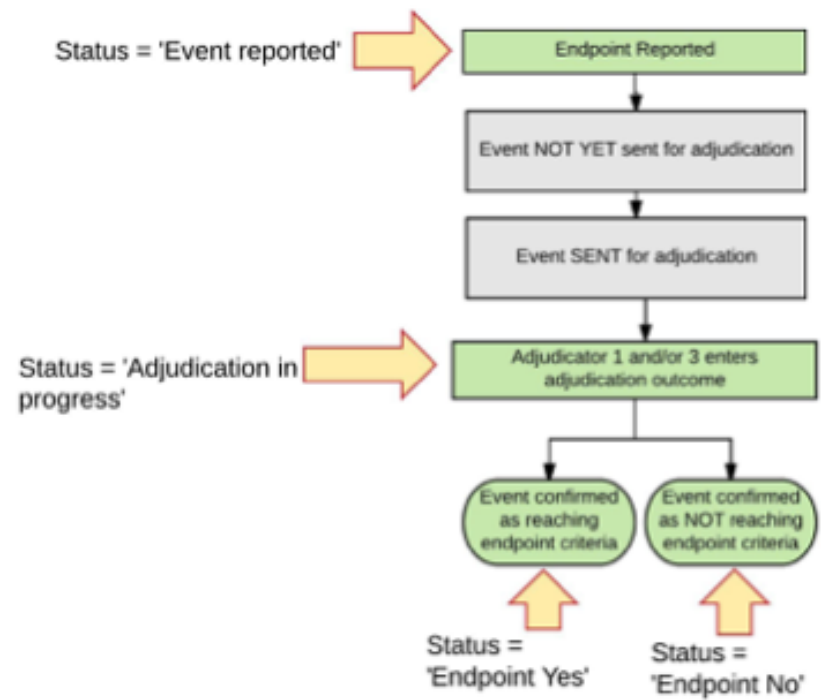
## 2. Progress reporting

The complexity of the progress report depends on the audience for the report.

# Example Workflow



# Example Workflow



Adjudication Progress Report 2

ENDPOINT Type	Events reported			Event SENT for adjudication			Completed Adjudications		ENDPOINT YES		ENDPOINT NO	
		Not yet sent for adjudication	%		%		%	% of adjudications		% of adjudications		
Event 1	771	390	51%	381	49%	356	46%	156	44%	200	56%	
Event 2	1024	84	8%	940	92%	889	87%	655	74%	234	26%	
Event 3	909	166	18%	743	82%	724	80%	398	44%	326	36%	
Event 4	491	228	46%	263	54%	208	42%	75	36%	133	64%	
Event 5	1289	28	2%	1261	98%	1233	96%	712	58%	521	42%	
TOTAL	4484	896	20%	3588	80%	3410	76%	1996	45%	1414	32%	



# 2. Progress reporting

In summary:

Constructing progress reports **is an academic task.**

It is a good idea to:

- Start complex and simplify
- Consider the transition points in the workflow
- Consider the important outcomes
- Consider the end user
- Provide a benchmark

## 2. Progress reporting

How do I determine the benchmark for a progress report?

Generally progress reports involve comparing the current accumulation of something against its expected quantity, or a Key Performance Indicator (KPI).

KPIs are the gold standard for progress reports.

KPIs in progress reports relate to how well your 'real world' workflow matches up with your ideal workflow.

KPIs could be raw numbers, timeframes, proportions *etc*

***Clinical benchmarking is a different thing altogether.***



# 2. Progress reporting

How do I construct a KPI?

Different for different studies.

In general, it is a good idea to:

- Consult with study staff or whoever is currently doing the work
- Establish activity targets (may or may not match up with what staff are recurrently doing)
- Define the data that staff need to track their progress



# 2. Progress reporting

How do I construct a KPI?

**Remember, workflows answer question....and so should KPIs**

**Is the study on track to meet study timelines?**

What proportion of GPs contacted by study staff are agreeing to participate?

How many GPs have been recruited so far?

If we keep recruiting GPs at the same rate, will we meet recruitment targets?

How many randomisations per week have been achieved in the last 6 weeks?

If we continue to randomise at the same rate, how long will recruitment take?

# 2. Progress reporting

How do I construct a KPI?

**Remember, workflows answer question....and so should KPIs**

**Is the overall data quality acceptable?**

Across the whole study, how many pieces of data are currently missing?

How much of the data entered is outside of the acceptable range?

Are any staff members producing significantly more data queries than others?

# 3. Technology





# 3. Technology

What technology should be used for progress reporting?

- Lots of different options re technology
- Use something that you (or the person preparing the report) knows how to use

Open source technology is a great option for studies on a budget.

The software is free!

It generally comes with a community.

# 3. Technology

## ASPREE and R

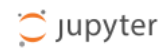
- In 2017, ASPREE decided to start transitioning to R
  - No licensing issues!
  - More plug-ins!
  - Flexibility!
- We had no previous experience using R (although Jason used Python)
- None of the ASPREE data team (excluding our programmer) are IT trained

# 3. Technology

## ASPREE and R progress to date

It has been fun!

We use Jupyter notebook and Rstudio



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Data				a day ago	
Week 1 - Introduction to Jupyter Notebook and R.ipynb			Running	21 days ago	9.94 kB
Week 2 - Creating data using R.ipynb			Running	a day ago	14.9 kB
Week 3 - Importing and viewing data.ipynb			Running	a day ago	17.9 kB
Week 4 - Selecting columns and performing basic statistics.ipynb			Running	a day ago	17.3 kB
Week 5 - Generating tabular data.ipynb			Running	a day ago	13.6 kB



# 3. Technology

jupyter Week 3 - Importing and viewing data Last Checkpoint: Yesterday at 14:45 (autosaved)  Logout Control Panel

File Edit View Insert Cell Kernel Widgets Help Trusted | R

## Week 3 - Importing data and using data frames

This week we will learn how to import data using R and how navigate a data frame.

The content for this week builds on principles from last week. So, if you need to familiarise yourself with the content from last week...now is a good time to do it!

Let's go!

### Before we get started...

**Important** Please make a copy of this notebook first so that you can save your progress as you go. To do this, click **File > Make a Copy...**, and then rename the notebook by clicking the notebook title to the right of the Jupyter logo at the top of the page. After duplicating this notebook, the title should default to "Week 3 - Introduction to Jupyter and R (Part 2)-Copy1". **If you do not do this, changes you make to the notebook will not be saved!**

### Importing data

Last week we compiled a data frame for 4 study participants (John, Mary, Peter and Ingrid) by manually typing the data values.

This is a reasonable way to input data into R for a small data set...but imagine if we had to enter data for 2500 participants or 19,000 participants!!

Luckily, there are lots of ways to get data into R other than manual input. One such way is to import data from another file, such as a csv using the read.csv function.

The code to use the read.csv function to import data:

```
name of data frame <- read.csv('file path ')
```

# 3. Technology

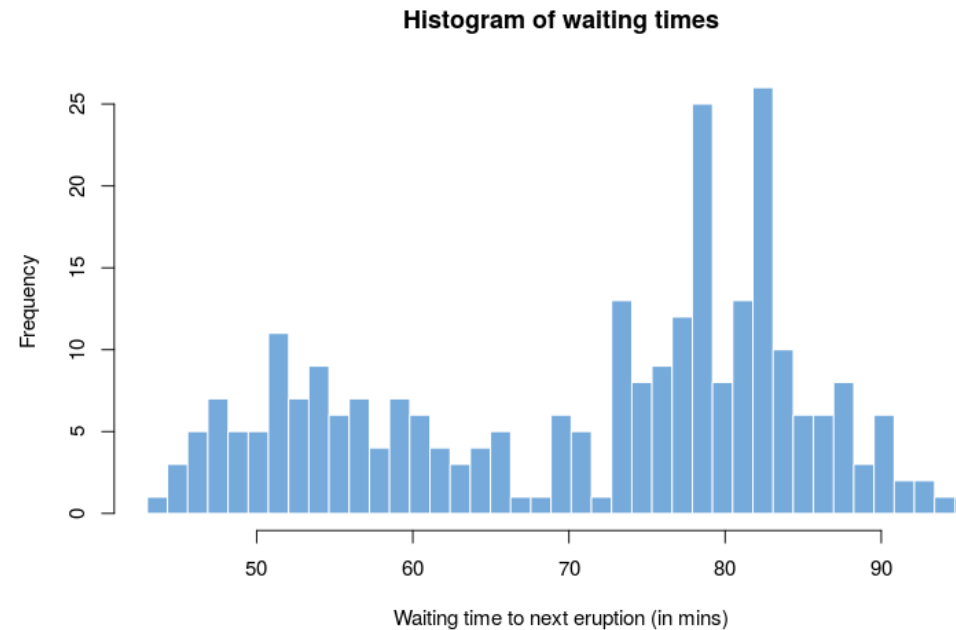
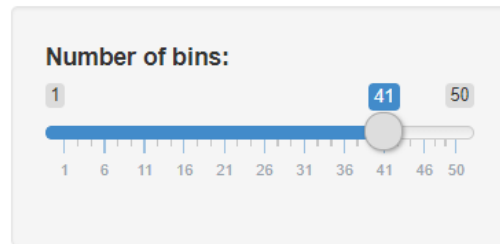
Using R provides opportunities to leverage reporting tools:

- R Shiny
- R Markdown

# 3. Technology

Using R provides opportunities to leverage reporting tools:

Hello Shiny!





# R markdown

E-Data/Jupyter%20notebooks%20(jrigby)/daily/2018-07-09/ccreporttemplate.html

☆

☆

## Commentary Code Report

Ashley Stewart  
16 July, 2018

### Commentary Code Report - Summary

Below is the summary of the commentary code report dated the 16 July, 2018 The table shows the total amount of data fields that are confirmed, the amount that are missing with the reaosn confirmed and the amount of fields left to be queried.

Type	Total	Percentage (%)
Confirmed	12763361	96.93
Missing	384237	2.92
In Progress	20571	0.16
Total	13168169	100.01

### Confirmed Data

Data in the logintudinal dataset that was either not out of range or has been queried and confirmed to be correct is shown in the table below.

CC	CC_Description	SectionA2	SectionB2	SectionB3	SectionB4	SectionB6	SectionC1	SectionC2	SectionD1	SectionE1	SectionE2	SectionE3	SectionG2	SectionH1	Totals	Query Confirmed (%)
0	Data provided and not out of range	481616	1238490	336997	818023	431662	2246612	471358	484537	4097820	880718	1093148	71741	76403	12729125	95.54
8	Data out of range, confirmed correct	132	2876	0	3916	0	0	18	1529	0	0	0	0	1336	9807	0.06
11	Categorical Data	118	0	0	14722	0	0	0	0	0	0	0	0	0	14840	0.11
13	Change Over Time Query - Confirmed	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0.00
20	Out of range over time - confirmed	0	1287	0	5049	0	0	669	2584	0	0	0	0	0	9589	0.07
Total	•	481866	1242653	336997	841710	431662	2246612	472045	488650	4097820	880718	1093148	71741	77739	12763361	95.78

### Missing Data

Data in the lognitudinal dataset that is missing and has been queried as to why it is misising is shown in the table below. This can include reasons

# R markdown

## Dementia Report

*Includes all triggers between March 2010 and 17 July, 2018*

Total Amount of Triggers from ASPREE Visits  
The table below describes the total dementia triggers by trigger type. 3MS triggers account for 52% of all triggers.

	3MS Annual Score below 78	3MS Annual Score drop > 10 pts	Dementia is reported on AE	Dementia Medication is reported	Total
AUS	441	169	482	62	1154
US	53	36	72	31	192
Total	494	205	554	93	1346

Dementia Assessment Progress  
Where possible a dementia assessment visit is conducted on all genuine dementia triggers. The table below shows the completed assessments and the reasons that other dementia assessments have not been completed.  
In total 56% of Dementia Assessments have been completed. 10% are awaiting completion. 34% could not be completed because the participant either declined or their follow up status was inappropriate.

Complete		Not Yet Completed			Unable to Complete			Total
		Confirmed, not contacted	Confirmed: pt willing	Not Reviewed	Trigger Provisionally Approved	Confirmed: pt unwilling	Pt status inappropriate	
AUS	619	15	2	104	4	136	274	1154
US	132	11	5	0	0	19	24	192
Total	751	26	7	104	4	155	298	1346

# 4. Demonstration

Dementia report demonstration





# 4. Demonstration

Site report demonstration



# 4. Demonstration

Staff report demonstration



# Summary

- Operational report is essential for tracking study progress
- Study activity can be organised into workflows
- Workflows are the basis for progress reporting
- There are lots of options re technology that can be utilised for reporting
- Open source products are a good option for some studies
- R has changed the way ASPREE approaches reporting
- R has lots of packages and tools that allow (non IT trained) researchers to rapid produce progress report templates that can be re-run at any time



# Questions?





