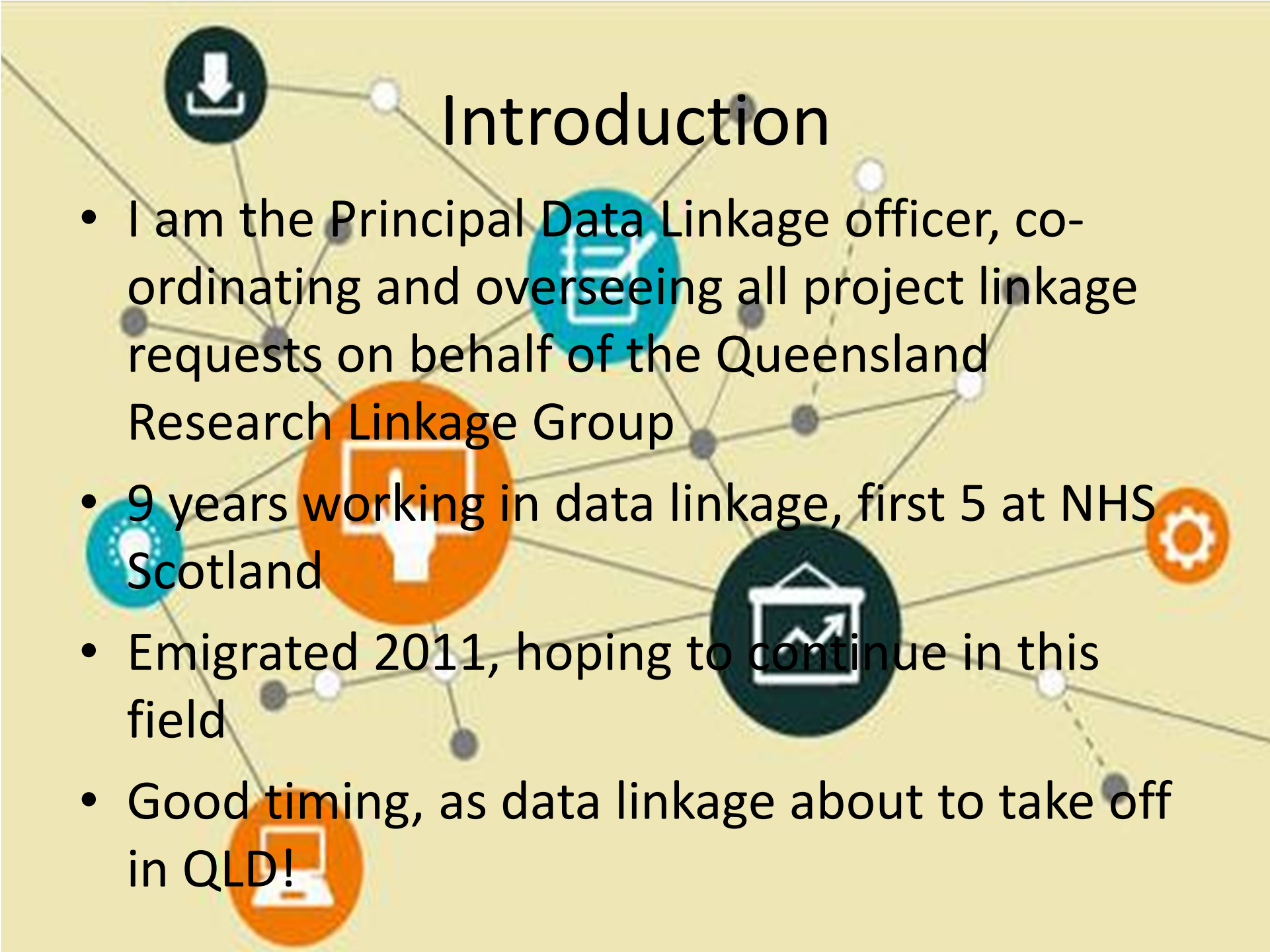


When will I receive my linked data??

A presentation from the heart of the data linkage request team

Catherine Taylor

2015 Data Linkage Symposium,
Brisbane

A network diagram background with various icons. The icons include a download arrow, a document with a checkmark, a person with a checkmark, a laptop, a gear, a house with an upward arrow, and a globe. The background is a light yellow color with a network of grey lines and nodes.

Introduction

- I am the Principal Data Linkage officer, coordinating and overseeing all project linkage requests on behalf of the Queensland Research Linkage Group
- 9 years working in data linkage, first 5 at NHS Scotland
- Emigrated 2011, hoping to continue in this field
- Good timing, as data linkage about to take off in QLD!

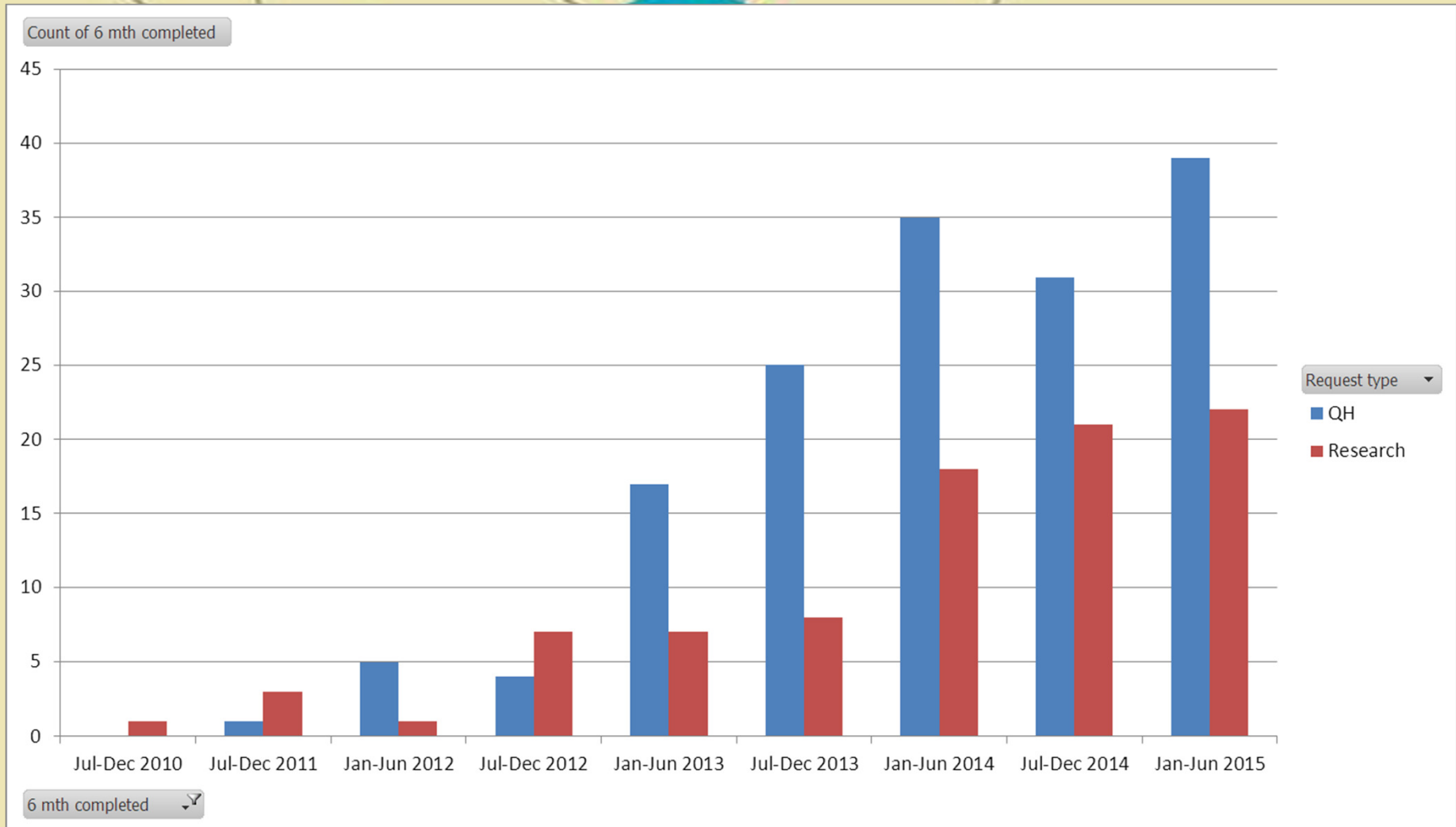


Data Linkage in Queensland

- Two data linkage teams – production (master linkage file), and requests
- I will give some information on the master linkage file, but will mainly focus on requests side
- Both teams very busy as interest in linked data grows – new data added to master linkage file, and volume (and complexity) of requests is increasing



Linkage projects completed 2010-2015





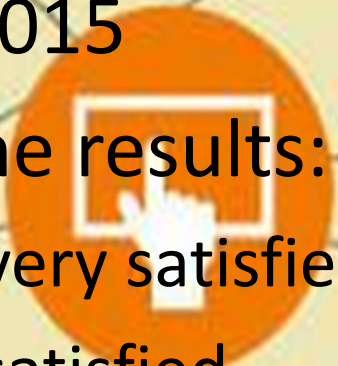
Master linkage file - benefits

- Ready-linked and quality-checked
- Request team can use this resource when the request parameters fit within MLF coverage
- It can at least reduce burden of a request involving longer period/other data sources
- We can get through more requests – researchers receive output more quickly



Client satisfaction survey

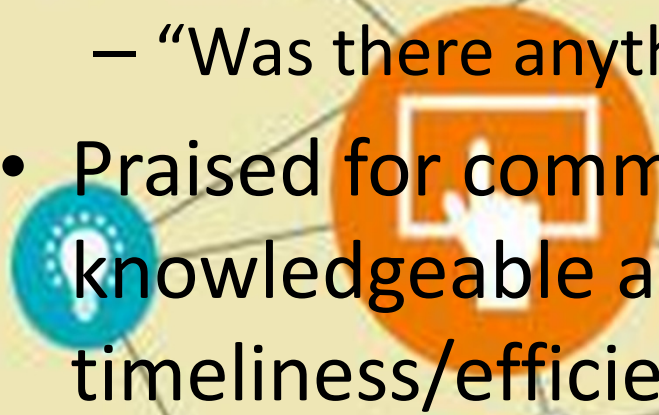
- Part of NCRIS/PHRN reporting requirements to survey clients who received linked data in 2014/2015
- **Headline results:**
 - 70% very satisfied
 - 30% satisfied
 - None neutral/dissatisfied/very dissatisfied





Client satisfaction survey

- Comments:
 - “Was there anything we did particularly well?”
 - “Was there anything we could have done better?”
- Praised for communication, being knowledgeable and helpful, and timeliness/efficiency
- Most common criticism was time taken to complete data linkage request



How long does a linkage take?

- Types of request – research (PHA or consent), QH internal
- Two extremes:
 - A recent research request took 4 hours as data already linked in MLE, minimal output
 - Another research request has been ongoing for 10 months, one person full time plus another helping
- Each project has its own timeline depending on a number of factors

What's involved in a linkage project?

- Cleaning and standardising data for linkage
- Plan of attack for complex linkages
- Actual linkage process
- Most time consuming: checking grey area
- Sense checks and fixing any anomalies
- Extracting, formatting, manipulating output
- Writing a brief report
- Checking of entire process by peer

Other factors influencing time taken



- Care taken to ensure quality
- Complexity
- Volume of data involved
- Quality of data
- Delays in receiving data
- Staff resources
- “Drop everything” requests

What complicates a linkage?

- Long periods of time covered – changes in data over time, quality issues
- Many data sources (especially in combination with above)
- Long lists of research variables to output
- Calculation of non-standard information such as length of stay in ICU, flagging re-admissions

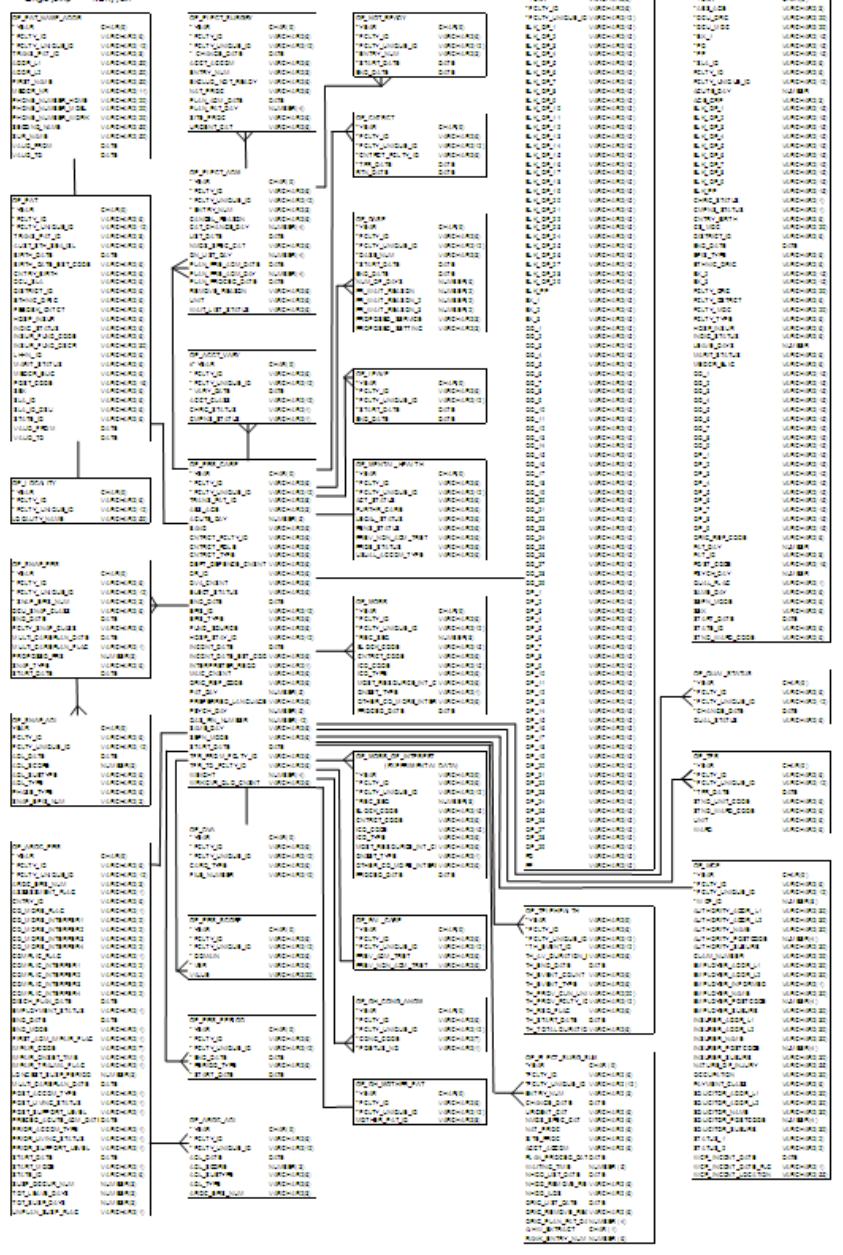
Don't you just push a button to get an extract?


- No!
- There is no easy pick-list of research variables
- We use SQL code to select each variable from relational Oracle tables
- Many-to-one relationships (diagnoses, procedures, wards etc.) further complicate
- We also need to add descriptions for coded variables



Diagram: MORBIDITY (SHARD)
Title: OE_MORB
Modified: 2 August 2011

Only latest data. Updated Second Sunday of each month.
- Single patient -



A network diagram with a light yellow background. It features several circular nodes connected by thin grey lines. The nodes contain various icons: a dark blue circle with a white download arrow, a teal circle with a white document icon, a large orange circle with a white document and arrow icon, a dark blue circle with a white calendar icon, a teal circle with a white lightbulb icon, a teal circle with a white laptop icon, and an orange circle with a white gear icon. The text 'External delays' is centered at the top, and a bulleted list is positioned to the left of the central orange node.

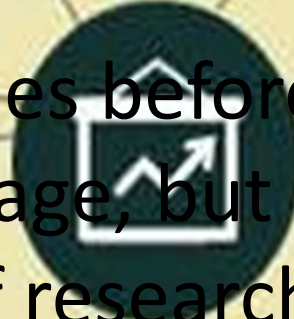
External delays

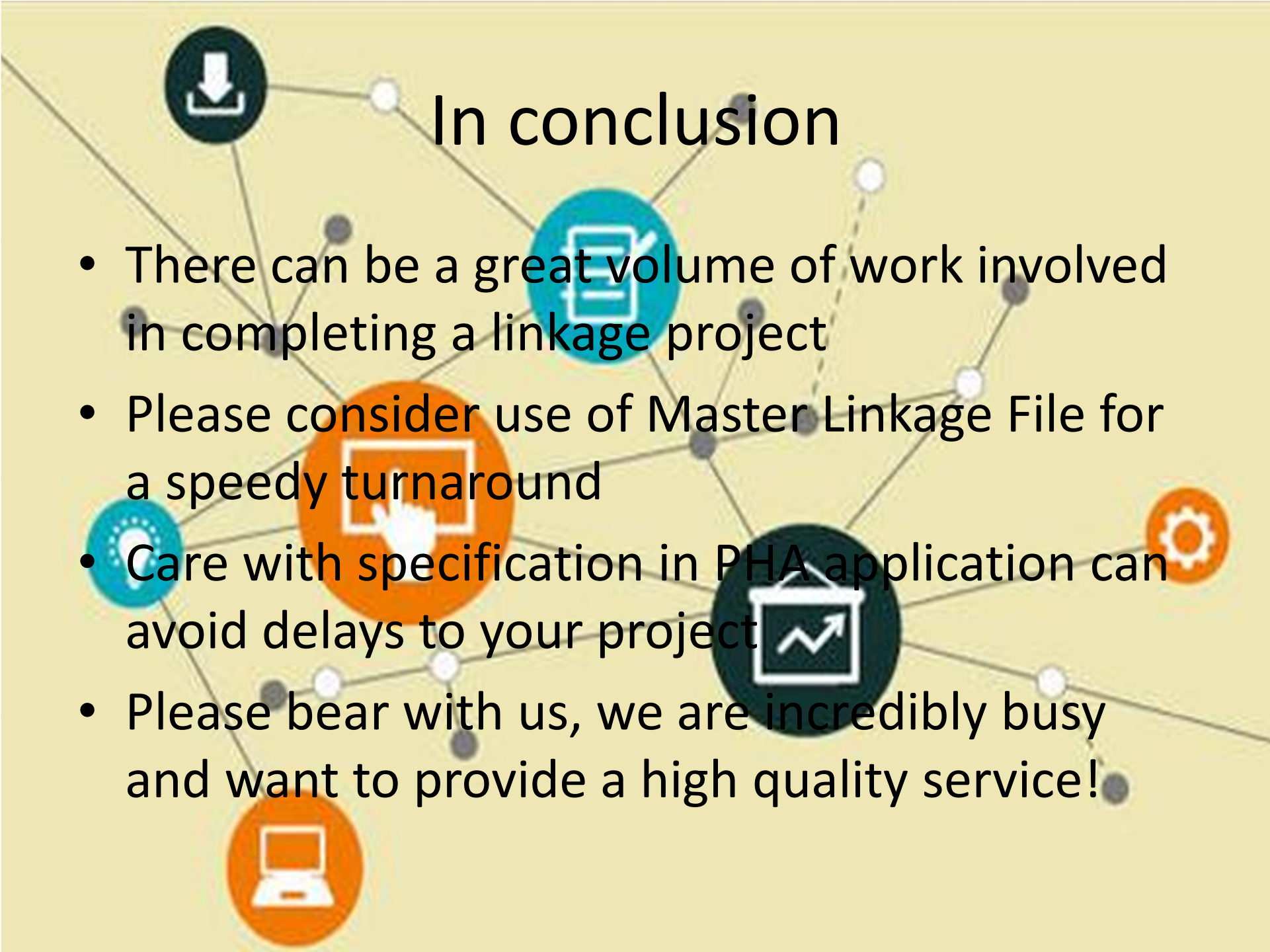
- Awaiting other custodians' data
- Incorrect extracts provided
- Issues with approved request – crucial variables/codes not specified – requires amendment, re-approval and sometimes re-work of linkage



PHA amendments


- Cause of longest delays, and increasing in frequency
- Vital to include everything needed for study in writing, in the PHA application - we can't provide anything not approved
- Occasionally we spot issues before approval, or while undertaking linkage, but we are not specialists in your field of research!
- Amendments can cause delays for other researchers!



A network diagram background with various icons. The icons include a download arrow, a document with a pencil, a hand pointing at a screen, a lightbulb, a gear, a laptop, and a calendar with an upward arrow. The nodes are connected by lines, and the background is a light yellow color.

In conclusion

- There can be a great volume of work involved in completing a linkage project
- Please consider use of Master Linkage File for a speedy turnaround
- Care with specification in PHA application can avoid delays to your project
- Please bear with us, we are incredibly busy and want to provide a high quality service!



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