

Data collection, extraction, and central collation

Induction Event

Plan for induction event for CAMHS PbR Pilots

- 11:00–11:10 **Introduction to PbR and pilot phase of project** (Miranda)
- 11:10–11:30 **Data needed from sites** (Katy)
- 11:30-11:40 **Data upload procedures** (Mike)
- 11:40–12:00 **Discussion of current systems in use** (Miranda)
- 12:00–12:20 **Demonstrate databases: CODE** (Jenna)
- 12:20–12:40 **Demonstrate databases: COMMIT** (Nadia/Mike)
- 12:40–13:00 **Support Team & Clinician Training** (Melanie, Katy and Rebecca)
- 13:00–13:30 **Q & A**

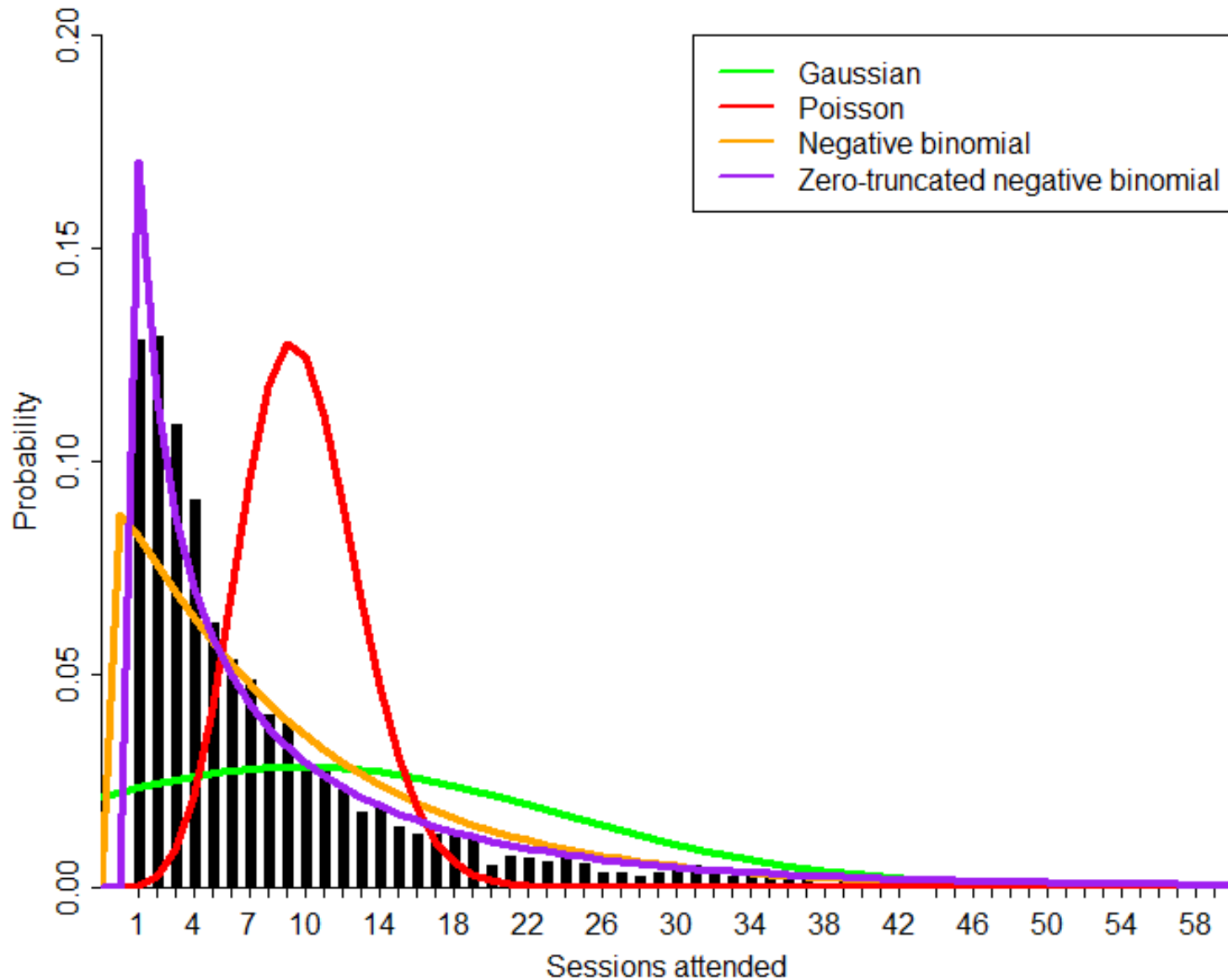
Introduction

- PbR is about resource needs
- Goal is to develop an algorithm which predicts resource needs as a function of early assessment information
- Leading to clinically meaningful resource groups
- Then linked eventually to costings – but that's a long way off

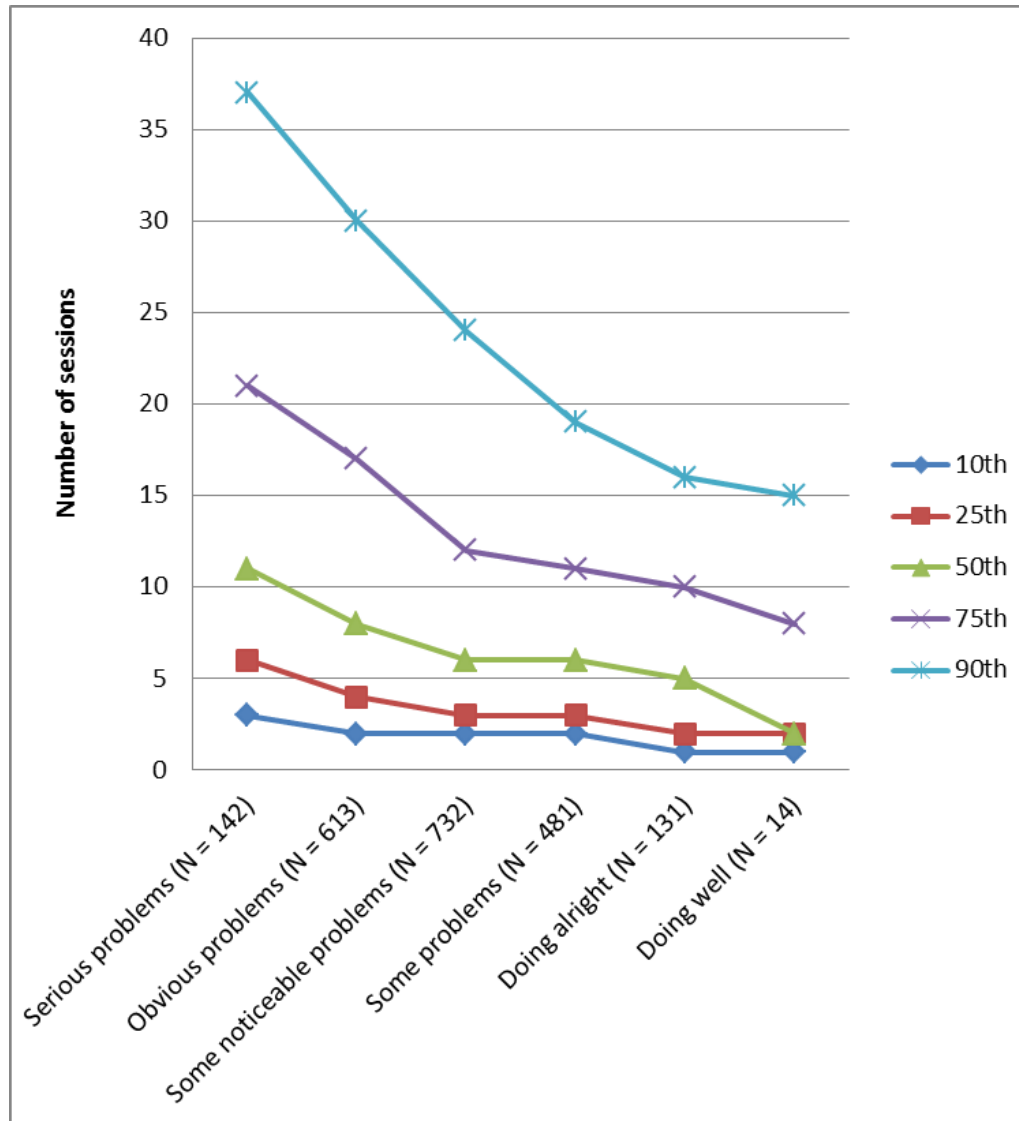
Outline

- Building on the Children and Young People's Improving Access to Psychological Therapies (CYP IAPT) dataset and processes:
 - Assessment
 - Activity information
 - Outcome measures (includes all commonly used CAMHS measures, e.g., SDQ, CGAS, RCADS)
 - Data transfer approach
- CAMHS PbR group suggested minor changes to IAPT spec – which were accepted
- Version 2 of dataset to be released later this year

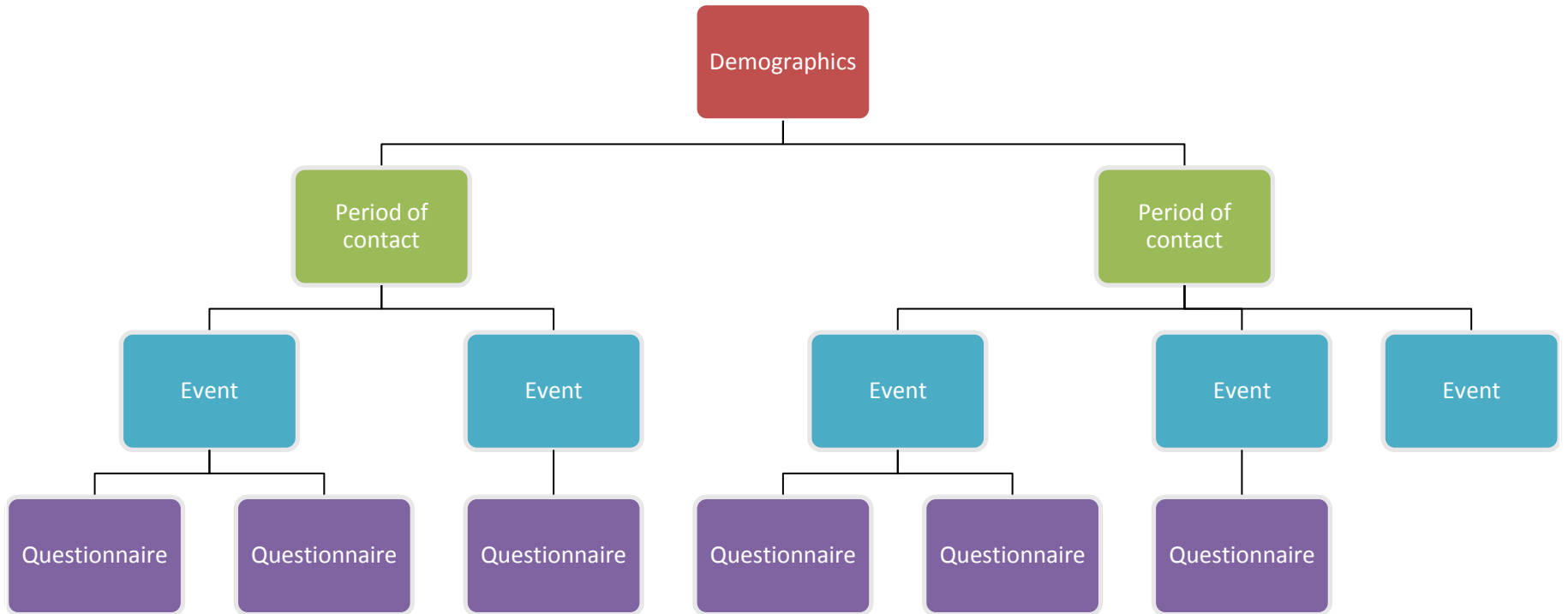
The flavour of analyses: modelling resource usage...



For instance modelling resource usage by severity of problems



Data hierarchy

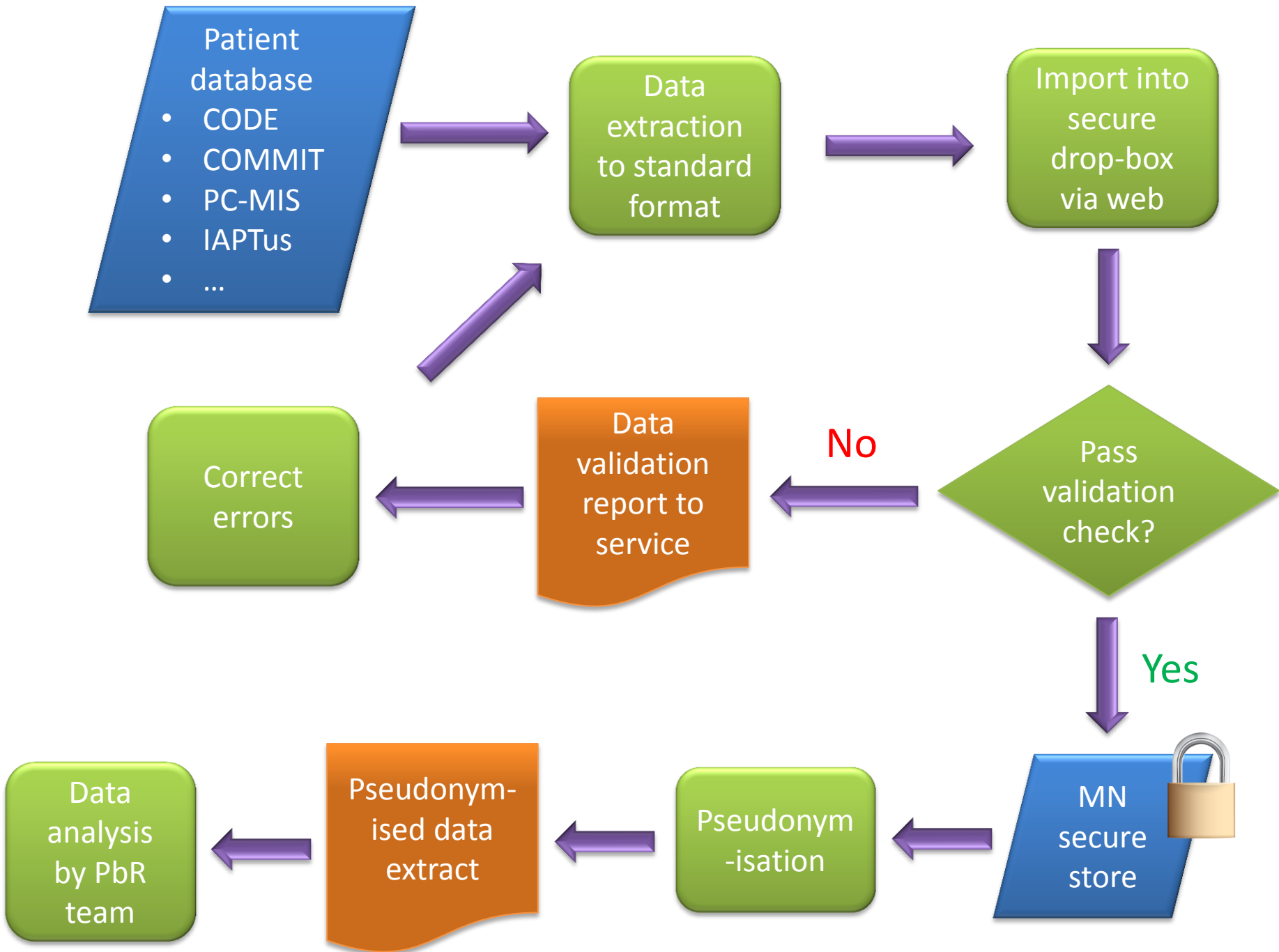


	B	C	D	E	F
1	CYP IAPT Dataset Specification: input variables				
2					
3	Variable name	Variable label	Data entry guidance notes	Variable type	Values
4	Demographics				
5	NHS_ID	NHS ID	*Mandatory to have either (a) an NHS ID or (b) a service ID and a locally service-assigned patient ID, but cannot have both	String	
6	SERVICE_ALLOCATED_PATIENT_ID	Locally service assigned patient ID, used if and only if NHS number is not available. Assumed to be unique at local level but not across global dataset.		String	
7	SERVICE_ID	Service identifier, e.g., a trust or specific service		String	
8	DOB	The date on which a PERSON was born or is officially deemed to have been born.		Date	CCYY-MM-DD
9	GENDER	Gender	The classification is phenotypical rather than genotypical, i.e. it does not provide codes for medical or scientific purposes.	Category	0
10					1
11					2
12					999
13	ETHNICITY	Ethnicity	The ethnicity of a PERSON, as specified by the PERSON. Note: ETHNIC CATEGORY is the classification used for the 2001 census, replacing ETHNIC GROUP in the flows through the NHS-wide Clearing Service. The Office of National Statistics has developed a further breakdown of the group	Category	
14					A
15					B
16					C
17					
18					D
19					E
20	F				
21					G

The data specification

- Specifies what data should be collected
- What format it should take
- Example:

TRAUMATIC _EVENT	6. Disturbed by traumatic event (PTSD)	Ordered	0	no problem
			1	mild problem
			2	moderate some impact on life
			3	severe – affects life a lot
			888	don't know
			999	missing data



Windows for data submission

Quarter	Dates	Submission window
Q4 2012	October – December	1– 15 January 2013
Q1 2013 (Q4 refresh)	January – March	1–15 April 2013
Q2 2013 (Q1 refresh)	April – June	1–15 July 2013
Q3 2013 (Q2 refresh)	July – September	1–15 October 2013
Q4 2013 (Q3 refresh)	October – December	1– 15 January 2014
Q1 2014 (Q4 refresh)	January – March	1– 15 April 2014
Q2 2014 (Q1 refresh)	April – June	1–15 July 2014

Data to extract

Records which have been either

- Created, or
- Amended

during the submission period up to including submitted date

(Much) more detail at <http://www.iapt.nhs.uk/cyp-iapt/routine-outcome-monitoring-as-part-of-iapt/>

About MegaNexus

- UCL start-up founded 2003
- Provides secure data partnerships for highly sensitive data
- Collaborates with CORC and EBPU
- Core clients include
 - local government
 - the prison service
 - higher education institutes

Security

- Distributed over two data centres
- All in-transit data is suitably secured using HTTPS
- Meets highest information security standards
 - ISO27001 certified
- Externally audited by CESG
 - Software and infrastructure assessed and verified by CESG CLAS consultants

Upload process



Patients Submit Data Users Reports

Account Logout

Submit Data

Upload Files Export from COMMIT

New Import

Uploaded Files

Navigation: Show: 15 results

Date Created	Quarter	Note	Validation Status	Service/Partnership	View	Download
Results 31 - 45 of 79.						
03/07/2012 16:01:26	Q1 2012 (January to March)		Pending	Service		Download
03/07/2012 16:01:40	Q2 2012 (April to June)		Pending	Service		Download
03/07/2012 17:47:11	Q1 2012 (January to March)		Pending	Service		Download
03/07/2012 17:47:34	Q2 2012 (April to June)		Pending	Service		Download
03/07/2012 18:44:32	Q1 2012 (January to March)		Pending	Service		Download

Validation email example

This is a validation report for an import archive ('Q2.zip')
uploaded on 25/07/2012 16:33 by 'Admin'.

Errors for file: EVENT_20120725_154821_0#022_1#000.csv

Error: One or more values defined in the file failed validation,
please review these errors

* An invalid value was specified, a numeric value was
expected (error #-1764328910)

Column: position: 26 header: PRACTITIONER_2_ID

Row: 29 value: J0

Pilot Site Support Team

- Melanie Jones – Project Manager
- Katy Hopkins – Pilot Site Coordinator
- Rebecca Kyrke-Smith – Research Officer

What you can expect from us

- Support sites through all stages of the pilot
- Provide training and on-going support for clinical teams in the completion of PbR assessment tools
- Advise on completion of PbR dataset and validate data for compliance with CYP IAPT specification
- Troubleshoot data entry and upload issues
- Timely responses (both automatic and human!)
- Follow best practice for information security and analysis

A member of our team will be at each training event and we will provide follow-up support as required through a dedicated email address: pbrcamhs@annafreud.org

We are in the process of setting up a CAMHS PbR website.

Expectations from service leads

To ensure that:

- all involved in the pilot project receive training (either directly or through train-the-trainer)
- training is completed prior to start-up date (for sites that have opted for train-the-trainer)
- **all** clinicians use the PbR approach with **all new referrals** following start-up

Expectations from data leads

- Ensure IT systems are ready and able to upload by January 2013
- Responsibility for regular data entry
- Responsibility for service data quality
- Meet deadlines for data upload

Actions

- Make changes to IT systems
 - Ensure they can be ready in time for training
- Decide how to organise local data collection and entry
 - Who will enter data
 - When?
 - Which teams will be able take part
- Check with Caldicott guardian re information security requirements

CYP-IAPT Assessment Tool

Current View

Session N°



CYP Name: _____ NHS ID: _____

Practitioner's Name: _____ Practitioner's ID: _____

PROBLEM DESCRIPTION	None	Mild	Moderate	Severe	Don't know
1 Depression/low mood (Depression)					
2 Behavioural difficulties (CD or ODD)					
3 Anxious away from home (Separation anxiety)					
4 Anxious in social situations (Social anxiety/phobia)					
5 Anxious generally (Generalized anxiety)					
6 Disturbed by traumatic event (PTSD)					
7 Compelled to do or think things (OCD)					
8 Panics (Panic disorder)					
9 Avoids going out (Agoraphobia)					
10 Avoids specific things (Specific phobia)					
11 Difficulties sitting still or concentrating (ADHD/Hyperactivity)					
12 Eating issues (Eating disorder)					
13 Gender discomfort issues (Gender identity disorder)					
14 Severe relationship difficulties (Emerging personality disorder)					
15 Problems in attachment to parent/carer (Attachment problems)					
16 Doesn't get to toilet in time (Elimination problems)					
17 Severe mental health issues (Psychosis or bipolar disorder)					
18 Self harm (Self injury or self harm)					
19 Drug and alcohol difficulties (Substance abuse)					
20 Repetitive problematic behaviours (Habit problems)					
21 Does not speak (Selective mutism)					
22 Carer management of CYP behaviour (e.g. Management of child with challenging behaviour)					
23 Family relationship difficulties					

Choose which most applies for CYP re. Home, School and Community context					
	None	Mild	Moderate	Severe	Don't know
HOME ISSUES e.g. family substance abuse					
SCHOOL ISSUES e.g. bullying					
COMMUNITY ISSUES e.g. violence					

SELECTED COMPLEXITY FACTORS	YES	NO	DO NOT KNOW
1 Looked after child			
2 Young carer status			
3 Learning Disability			
4 Serious physical health issues (including Chronic Fatigue)			
5 Pervasive Developmental disorder (including autism and Asperger's)			
6 Neurological issues such as tics or Tourette's			
7 Current protection plan			
8 Deemed "child in need" of social service input			
9 Refugee or asylum seeker			
10 Experience of war, torture or trafficking			

- Some minor changes in progress
 - Additional complexity factors
 - Additional presenting problems