

ICTM All Staff meeting

Nick Thomas
Institute Manager

31st July 2018

Agenda

	Welcome	Nick Thomas, Institute Manager
10:00	EDIT (Equality, Diversity and Inclusion Team) update	James Blackstone, Trial Manager
10:10	ICTM Staff survey Action Plan	Nick Thomas, Institute Manager
10:20	CCTU RISAPs OPTIMAS Adept	Ana Quartilho, Statistician Kate Bennet, Statistician Sophie Connor, Clinical Project Manager
10:35	Paediatrics, Infections, MRC CTU Impact of the introduction of HIV testing at birth on early infant diagnosis in KwaZulu-Natal, South Africa, 2010-2017 Severe immunosuppression and viral failure in adult care among antiretroviral therapy-experienced young people with perinatal HIV in the UK	Lizzie Chappell and Hibo Asad, PhD students
10:50	HR Update	Carole Booth, HR Manager
11:00	General Data Principles Regulation update	Lailaa Carr, Research Contracts Manager
11:15	Estates update	Rachel Martino, MRC CTU Unit Manager
11:25	Closing remarks	Nick Thomas, Institute Manager

Equality, Diversity and Inclusion Team (EDIT) Update

James Blackstone

31 July, 2018

Rebranding

The Athena SWAN committee has been rebranded as:

The Equality, Diversity and Inclusion Team (EDIT)

to best reflect our ongoing role, which continues to embody and push for Athena SWAN goals

Mentoring

Two training events for mentoring held in early July:

- Attended by ICTM, ICH, IWH staff
- Both sessions were fully booked
- uMentor will be formally ending at UCL.
Expectation is that inter-institute matching of mentors and mentees will be available in due course
- Thanks to Sarah, Lizzie, and Carole

Early Career Network

‘A Day in the Life of...’ ICTM Event

- Held in late June; 70 attendees
- 4 speakers from CTU and CCTU:
 - Statistician
 - Trial Manager
 - Clinical Project Manager
 - Data Scientist
- Thanks to Lindsay, Mags and Louise presenting
- Gosala, Katherine and Saba organising

Wellbeing

Working group of 15 ICTM staff

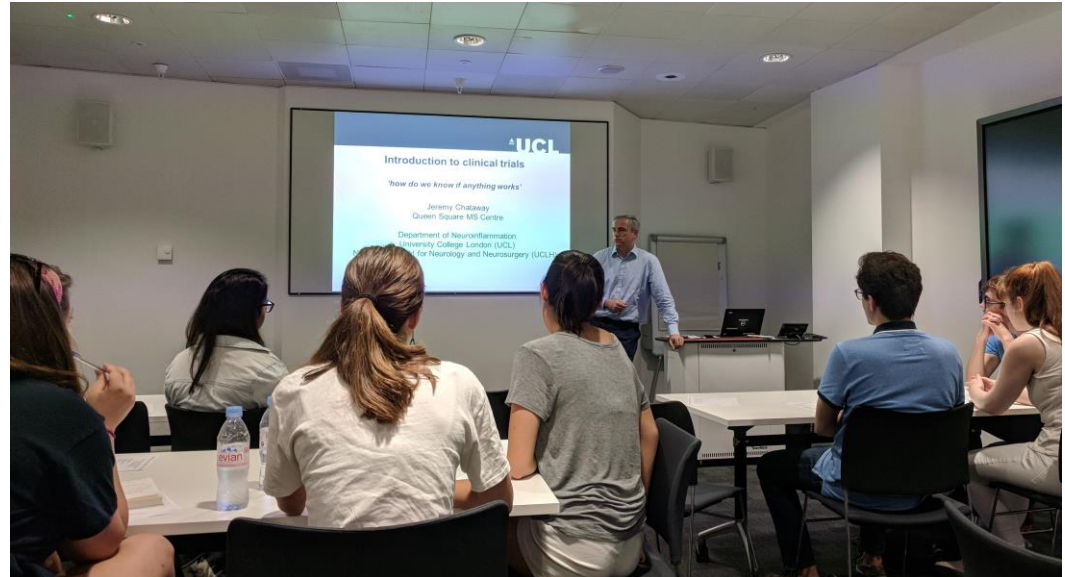
Sub-groups focusing on the following areas:

- Physical health – Occupational Health: exercises at one's desk
- Mental health – activities for Mental Health Awareness week and meal event in October
- Social – office events, bake-sales
- Learning – conferences, online resources for staff
- Giving Back – volunteering; possible use of 90HH courtyard

Outreach activities – A-level Student Event

CCTU combined with MRC CTU to host the 'clinical trials' day of an A-level student outreach week, run by the Institute for Women's Health.

- 17 students / a full-day session in early July
- 4 presenters from CCTU / 7 from CTU
- Student feedback indicated that:
 - For almost all this was their first real experience of hearing about trials
 - Several noted the experience was more helpful for them in terms of careers than IWH sessions



Submission timelines

Sept 2018

- Nominate individuals to complete sections of the application form
- Collation of data
- Staff Survey opens

Oct 2018

- Staff Survey closes
- Collation of data
- Analysis of staff survey

Nov 2018

- Analysis of staff survey and review
- First draft of application

Dec 2018- Jan 2019

- Discuss progress with draft application and any areas that still need improvement
- Review action plan, make any updates and identify
- Discuss any final actions to be implemented or planned before the submission deadline.
- Send draft for review- central UCL

Feb- Mar 2019

- Make any amendments to the application based on feedback
- Send second draft for review- central UCL
- inform UCL of intention to submit in April
- Final amendments and review of application
- Final draft of application gets signed off by Director

30 April 2019

- Submit Application


Staff Survey Action Plan

Nick Thomas
Institute Manager

Staff Survey 2017

Key Points

- Overall Response Rate – 63%
- Responses - 142/232
- Employee Engagement Score 69%

 TOP 3 HIGHEST SCORING QUESTIONS:	% POSITIVE
Q2. I understand how my work contributes to the objectives of my department/division	94%
Q4. The people I work with co-operate to get the work done	91%
Q33. As long as I get the job done, I have the freedom to work in a way that suits me	89%

What's Next?

45%

of employees replied favourably to:

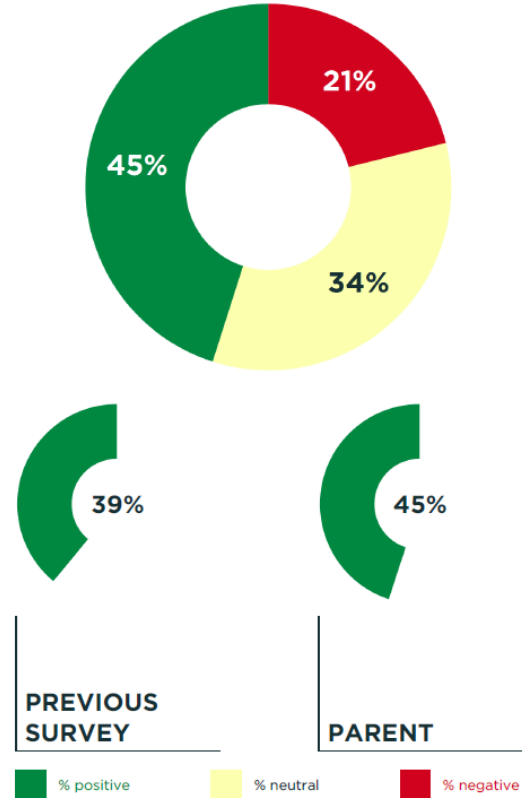
**'I believe that
action will be
taken on this
survey.'**

VARIANCE
FROM
PREVIOUS
SURVEY











+6↑

VARIANCE
FROM
PARENT

0



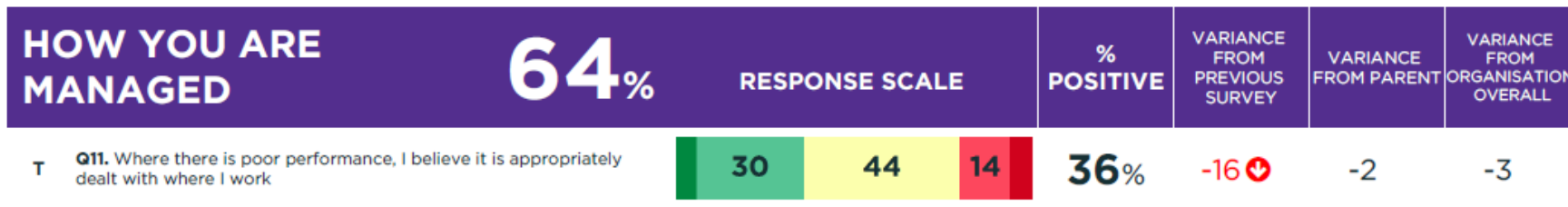
1 – Bullying and Harassment

EQUAL OPPORTUNITIES	RESPONSE SCALE	RESPONSE COUNT	%	VARIANCE FROM PREVIOUS SURVEY	VARIANCE FROM PARENT	VARIANCE FROM ORGANISATION OVERALL
Q43. I have been subject to behaviour that I consider to be bullying/harassment in the last two years at UCL		142				
Yes		10	7%	+3	-6 	-9 
No		132	93%	-3	+6 	+9 
Q44. I have witnessed behaviour towards others that I consider to be bullying/harassment in the last two years at UCL		142				
Yes		24	17%	+3	-4	-8 
No		118	83%	-3	+4	+8 

1 – Bullying and Harassment

- Hosting “Where do you draw the line?” Sessions
 - Monday 10th September 18
 - Thursday 11th October 18
- Looking at local reporting processes, to ensure people feel confident to raise concerns.

2 - Managing Poor Performance



2 - Managing Poor Performance

- HR will be running further line management briefings, one of which will focus on how to manage poor performance.
- There are also a number of free to attend UCL courses to help managers;
 - Getting the Best out of People
 - Conflict Resolution Skills (Managers)

3 – Career Development

CAREER DEVELOPMENT		52%				RESPONSE SCALE	% POSITIVE	VARIANCE FROM PREVIOUS SURVEY	VARIANCE FROM PARENT	VARIANCE FROM ORGANISATION OVERALL
T	Q27. There are sufficient opportunities for training and development to improve my skills and grow at UCL	12	54	15	16	66%	+20 ↑	-5 ↓	+4	
K	Q28. I am encouraged to show initiative and be proactive at UCL	23	45	23	9	67%	-3	-4	0	
	Q29. The grading review process at UCL is applied fairly	15	55	18	9	18%	+2	-5 ↓	-4	
	Q30. I think 's promotions criteria are clear		48	30	14	54%	+16 ↑	+7 ↑	+6 ↑	
	Q31. I think UCL's promotions process is fair	27	48	16		32%	-3	+1	-4	

3 – Career Development

Academic and Research staff

- Continuing to run promotions workshops, to highlight criteria for promotion targeted at those eligible for promotions and their line managers.
- Embedding the promotions framework as part of the appraisal process, to allow objectives to be set in line.

3 – Career Development

Professional Service staff

- We are working on creating a career map for clinical trial professional services, highlighting career paths, with defined experience and behavioural requirements.
- Looking at how we can support staff develop skill sets in line with the career map across the Institute and supporting the development of individuals Personal Development plans during appraisals to be reviewed during the year.

RISAPS

Rivaroxaban for Stroke patients with
AntiPhospholipid Syndrome

Ana Quartilho

CCTU Senior Statistician, 31st July 2018

Why RISAPS?

Thrombotic antiphospholipid syndrome (APS) is a recognised cause of ischaemic stroke and transient ischaemic attacks (TIA)

DOACs are emerging as the standard of care in many thrombotic conditions

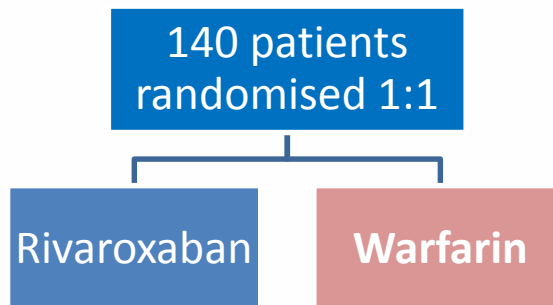
Recurrent thrombotic events with DOACs in APS patients mainly occur with standard intensity

In standard care APS patients are generally treated with high intensity warfarin

An appropriately designed and adequately powered trial is essential to establish the clinical utility of DOACs in stroke patients with APS.

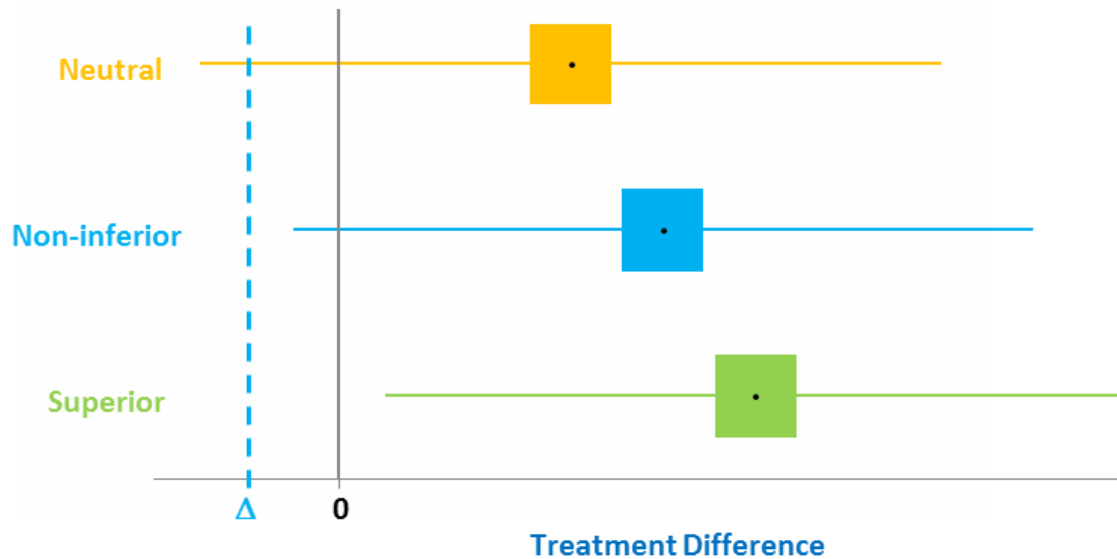
The RISAPS study

- **Design:** Non-inferiority, multi-centre, phase II/III RCT
- **Population:** Stroke patients with APS with or without SLE



- **Aim:** show that rivaroxaban is no worse or better than warfarin (standard of care)
- **Primary outcome:** change of MRI white matter hyperintensities (WMH) at 24 months

Non-inferiority trial



RISAPS team

- **Chief Investigator:** Prof Hannah Cohen, UCL/UCLH
- **Clinical Project Manager:** Zainib Shabir, UCL Comprehensive Clinical Trials Unit
- **Trial Manager:** Jade Dyer, UCL Comprehensive Clinical Trials Unit
- **Oversight Statistician:** Prof Caroline Doré, UCL Comprehensive Clinical Trials Unit
- **Trial Statistician:** Ana Quartilho, UCL Comprehensive Clinical Trials Unit



OPtimal TIMing of Anticoagulation after AF-associated acute ischaemic Stroke: a randomised controlled trial

Kate Bennett

CCTU Statistician, 31st July 2018

Why OPTIMAS?

- There are more than 150,000 strokes in the UK each year
- 30,000 of these are AF-related ischaemic strokes
- Anticoagulation reduces the incidence of recurrent ischaemic stroke and is currently the standard treatment in the UK

There is considerable uncertainty about the optimal timing of anticoagulation in AF-associated acute ischaemic stroke.

Early anticoagulation with DOACs (Direct non-vitamin K antagonist [VKA] oral anticoagulants) is promising but unproven.

Current UK guidelines recommend delaying anticoagulation for 14 days for “disabling” stroke to avoid haemorrhagic complications.

The OPTIMAS Study

Main hypothesis: early treatment (≤ 4 days) with direct oral anticoagulants is **safe** and **effective** after acute ischaemic stroke associated with AF.

Main aim: to determine the optimal timing of anticoagulation after acute atrial fibrillation (AF)-related ischaemic stroke, with important implications for treatment efficacy, safety and health economics.

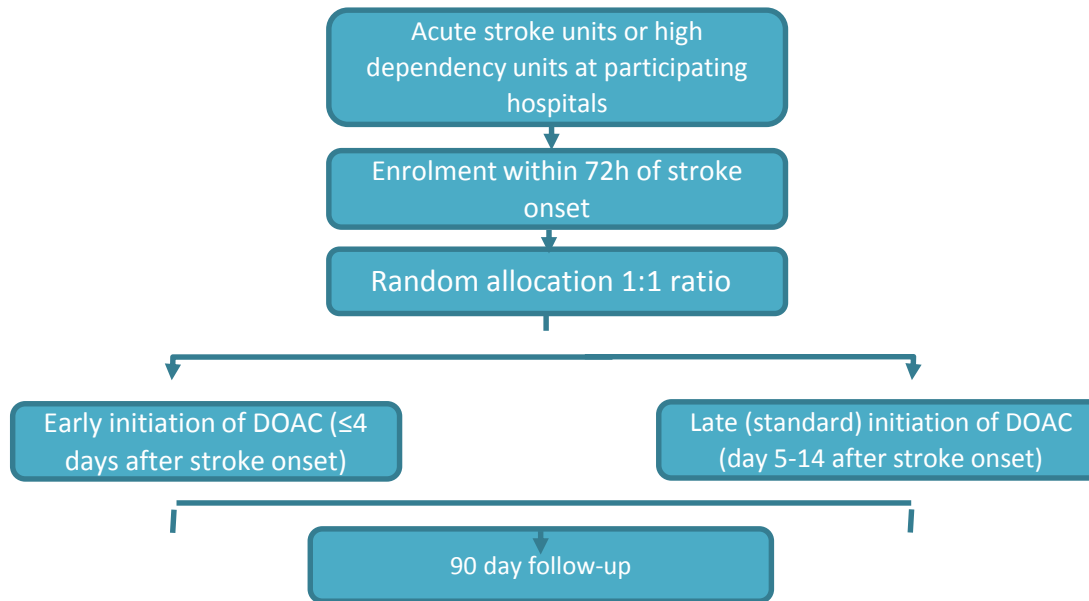
The OPTIMAS Study

Primary Outcome: Composite of recurrent ischaemic stroke, systemic embolism, or death within 90 days.

Secondary Outcomes:

- Intracranial haemorrhage (ICH)
- Major extracranial bleeding

The OPTIMAS Study Flowchart



The OPTIMAS Study

Funder: British Heart Foundation

Study design: Multi-centre, phase III, randomised controlled trial

Study population: Patients with AF-associated acute ischaemic stroke eligible for DOAC treatment

Target Sample Size: 3474 over 3 years, at 100+ UK sites

OPTIMAS Team

- **Chief Investigator:** Prof David Werring, UCL Institute of Neurology
- **Clinical Project Manager:** Marta Campos, UCL Comprehensive Clinical Trials Unit
- **Trial Manager:** Iwona Zaczek, UCL Comprehensive Clinical Trials Unit
Macey Murray, UCL Comprehensive Clinical Trials Unit
- **Data Manager:** Robert Fenner, UCL Comprehensive Clinical Trials Unit
- **Trial Statistician:** Kate Bennett, UCL Comprehensive Clinical Trials Unit

ADepT-PD

Antidepressants Trial in Parkinson's Disease

Sophie Connor

CCTU Clinical Project Manager, 31st July 2018

Why ADepT-PD?

- Depression affects 40% of Parkinson's patients
 - Linked to cognitive decline and faster disease progression
- Most common antidepressants:
 - SSRI (Selective Serotonin Re-uptake Inhibitor)
 - TCA (Tricyclic Antidepressant)

SSRIs vs TCAs

SSRIs

Lower risk of adverse events

May worsen Parkinson's symptoms

TCAs

Increased risk of adverse events

May delay Parkinson's disease progression

What type of study is ADepT-PD?

- Randomised 1:1:1
- 3 Arms:
 - SSRI (Escitalopram)
 - TCA (Nortriptyline)
 - Placebo
- Double Blind
- Recruitment target: 408 patients
- Number of sites: 30 sites across the UK

How will ADepT-PD run?



Patient Questionnaires

Carer Questionnaires

Clinical Assessment

Health Economics Questionnaire (CSRI)

Patient Medication Guess

What are the ADepT-PD outcomes measures?

- Primary outcome:
 - Depression symptoms measured by the Beck Depression Inventory II questionnaire at 8 weeks
- Secondary outcomes:
 - Depression symptoms measured at both 26 and 52 weeks
 - Quality of life
 - Overall clinical effectiveness
 - Motor and non-motor experiences
 - Health and social care resource
 - Assessment of patient awareness of allocated treatment

ADepT-PD Team

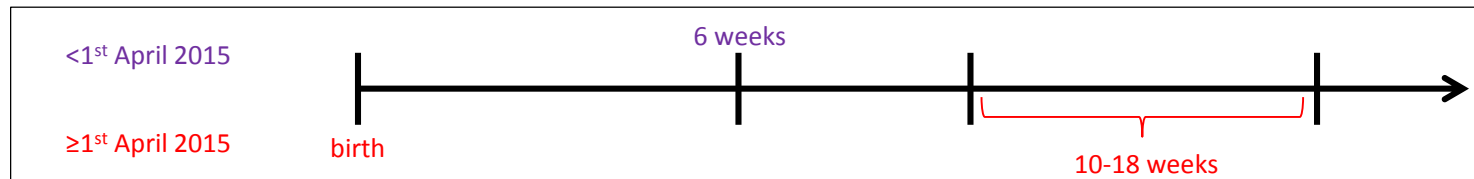
- **Chief Investigator:** Prof Anette Schrag
- **Clinical Project Manager:** Sophie Connor, UCL Comprehensive Clinical Trials Unit
- **Trial Manager:** Dr Helen Knowles, UCL Comprehensive Clinical Trials Unit
- **Oversight Statistician:** Prof Nick Freemantle, UCL Comprehensive Clinical Trials Unit
- **Trial Statistician:** Patrick Muller, UCL Comprehensive Clinical Trials Unit
- **Senior Data Manager:** Robin Carpenter, Priment CTU

Impact of the introduction of HIV testing at birth on early infant diagnosis in KwaZulu-Natal, South Africa, 2010-2017

Elizabeth Chappell, Kathy Baisley, Till Bärnighausen,
Jeannie Collins, Dickman Gareta, Diana Gibb,
Kobus Herbst, Claire Thorne, Ali Judd

Background

- WHO recommend testing HIV-exposed infants at 6 weeks of age, but too late to prevent:
 - early mortality in those infected, which peaks in the first 3 months of life¹
 - loss-to-follow-up
- Birth testing provides opportunity to diagnose infants and initiate ART early, but a follow-up test is needed to detect intrapartum infections
- South African guidelines recently updated:



- **Our objective:** To estimate testing coverage and adherence to testing guidelines from 2010-2017

¹ Bourne et al, AIDS, 2009.

Methods

- Hlabisa sub-district
 - Population of approximately 250,000
 - Antenatal HIV prevalence estimated at 46%¹ in 2015
 - 16 primary healthcare clinics, 1 district hospital
- Data on all PCR tests from 1st June 2010 to 17th July 2017 extracted from NHLS* database, with infants born to 31st December 2016 eligible for analysis



¹ The 2015 National Antenatal Sentinel HIV & Syphilis Survey, South Africa, National Department of Health.

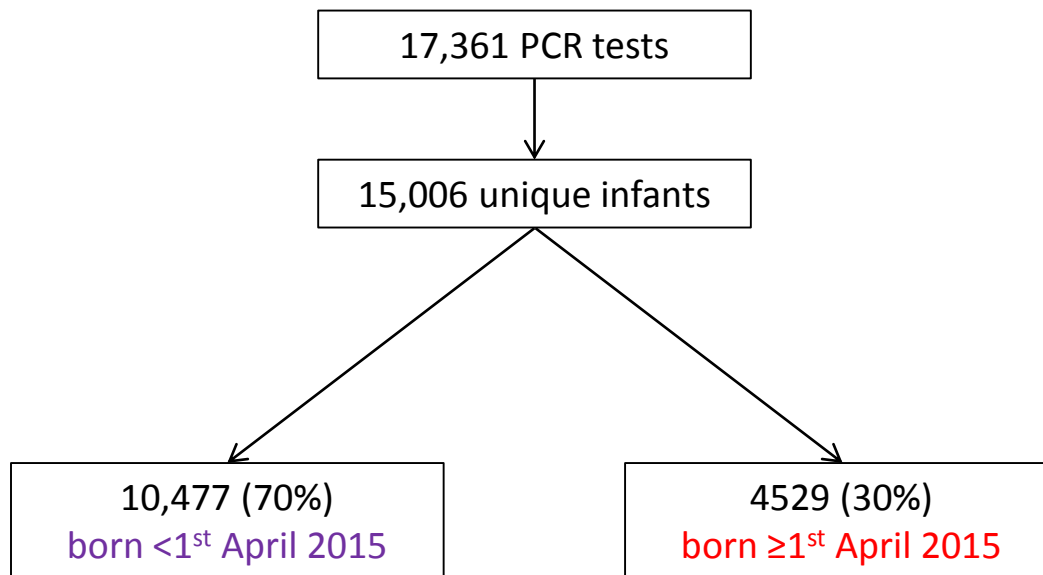
* National Health Laboratory Service

Methods

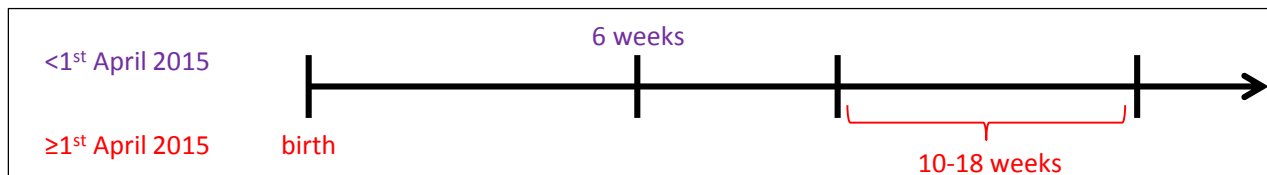
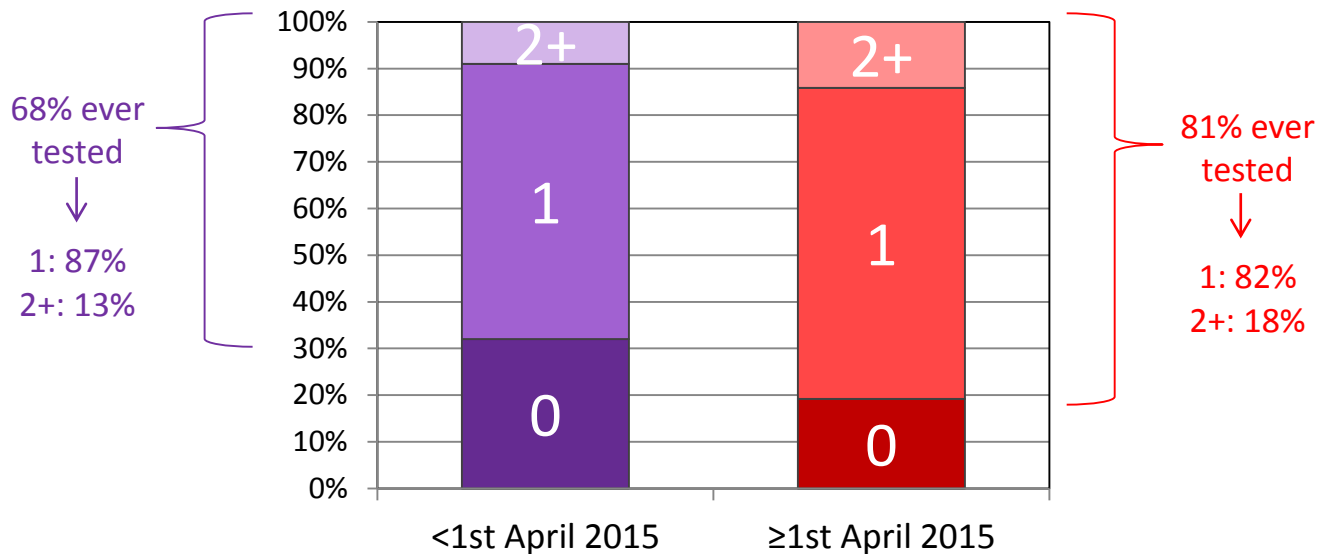
- Deterministic and probabilistic (Fellegi-Sunter method¹) linkage used to identify repeat tests on the same individuals, based on the following variables:
 - first name
 - surname
 - date of birth
 - clinic at which test taken
 - infant's clinic ID
 - sex
- Window of +1 week used to identify tests at birth, ± 2 weeks for other time points
- Proportion of HIV-exposed infants ever tested estimated using data from Statistics South Africa

¹ Fellegi and Sunter, Journal of the American Statistical Association, 1969.

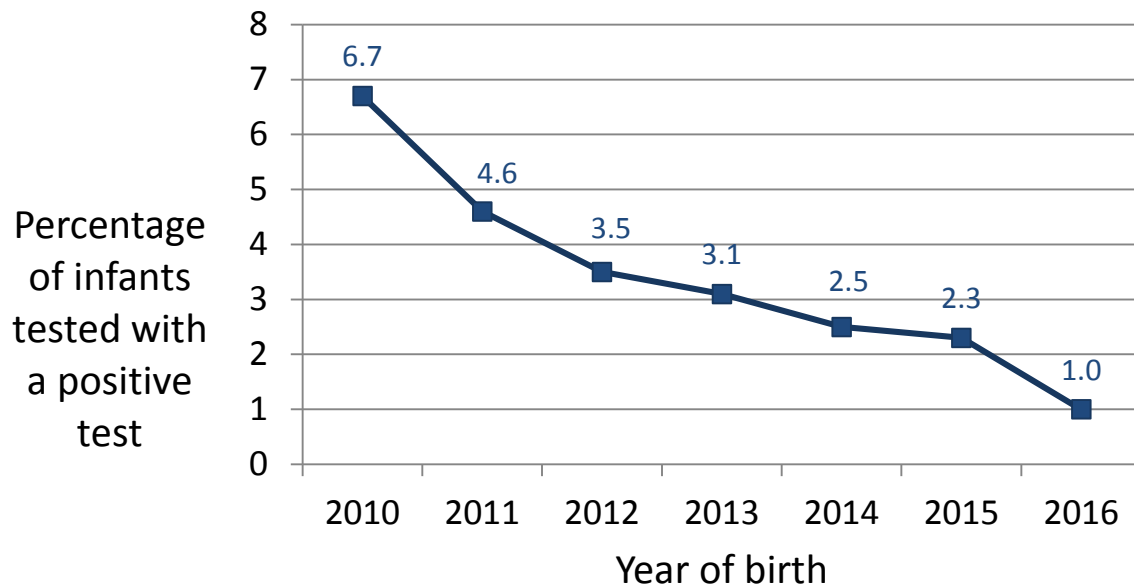
Results - linkage



Results - testing coverage

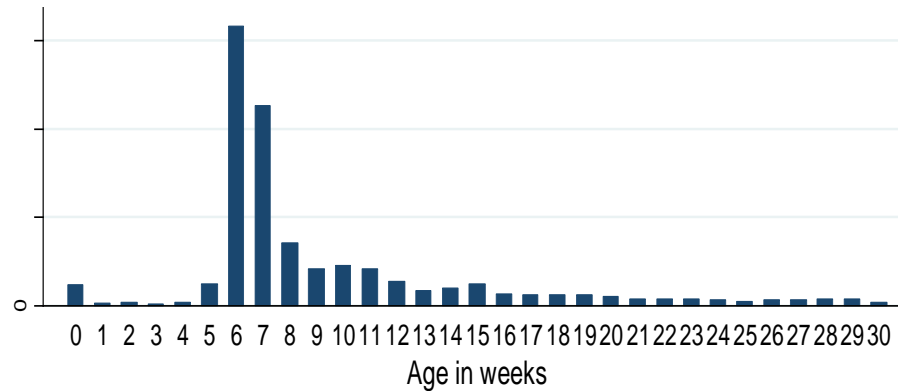


Results - proportion testing positive



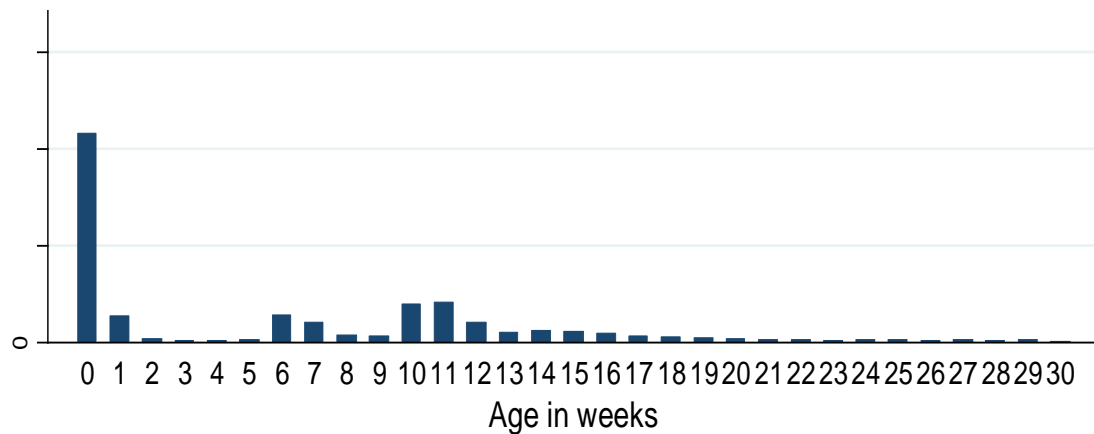
Results - testing under previous guidelines

- Median (IQR) age at first test was 7.0 (6.1, 11.0) weeks and at first positive test was 10.6 (6.7, 27.0) weeks
- 59% tested at 6 week visit, and 9% first tested after 6 months

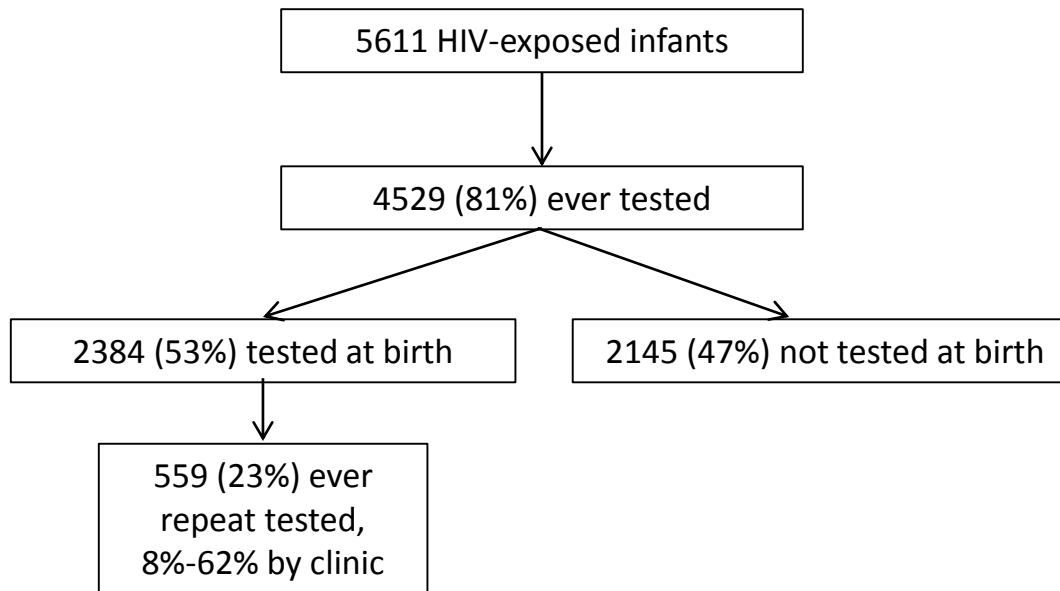


Results - testing under new guidelines

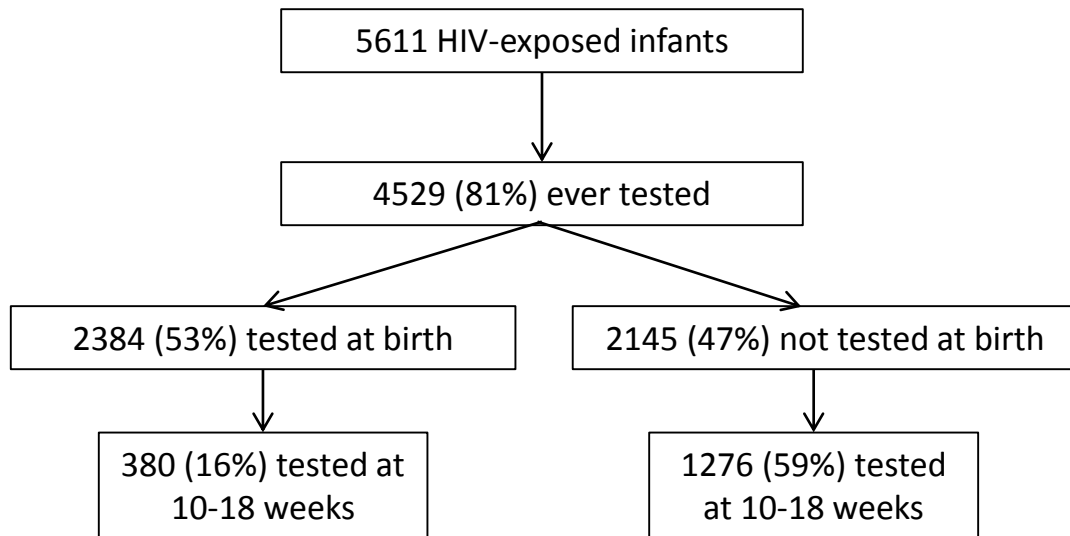
- Median (IQR) age at first test was 0.6 (0.0, 10.7) weeks



Results - testing under new guidelines



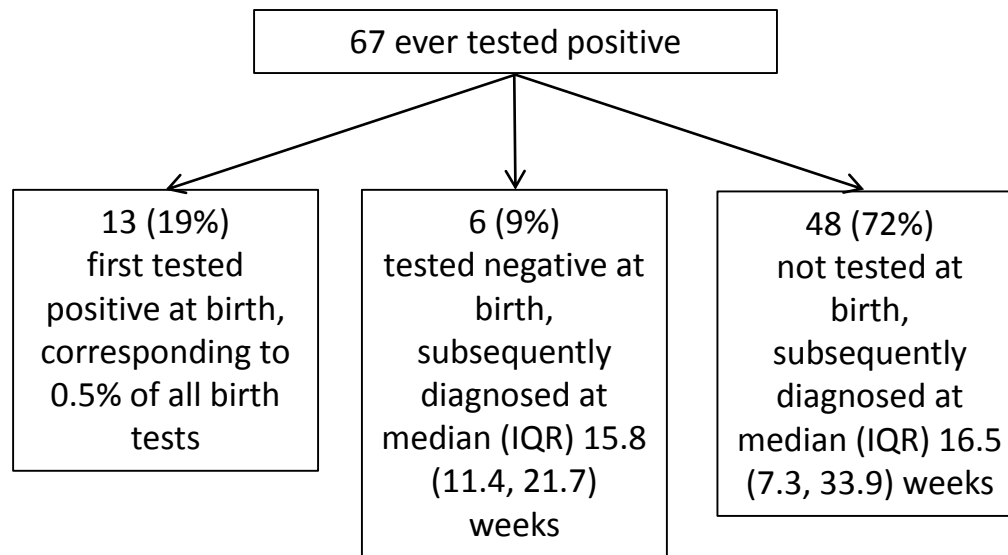
Results - testing under new guidelines



- No increase in the proportion tested at birth or in the proportion with a repeat test over time

Results - testing under new guidelines

- Median (IQR) age at first positive test was 13.1 (1.9, 29.1) weeks



- 45% (30/67) received a confirmatory PCR test a median 13 (7, 19) days later

Limitations

- Lack of unique identifier and poor quality of available identifying variable, may have led to underestimation of repeat testing and overestimation of testing coverage; a future validation study is planned
- Repeat testing may have been underestimated due to high levels of migration (22-31 per 1000 person-years)

Conclusion

- Although overall testing coverage increased after the introduction of birth testing, 20% of exposed infants still were never tested
- Less than a quarter of those testing negative at birth received a follow-up test with high variation by clinic - improved procedures required to follow-up infants after birth
- Increase in age at diagnosis worrying given early peak of infant mortality
- Proportion of infants testing positive fell over time, but lack of repeat testing likely to result in missed intrapartum infections
- Ongoing work will estimate the number of missed infections under each strategy as well as investigate predictors of testing

Acknowledgements

- The research leading to these results has received funding from the People Programme (Marie Curie Actions) of the European Union's Seventh Framework Programme FP7/2007-2013 under REA grant agreement n°612216
- This work is supported by an Medical Research Council studentship (programme number MC_UU_12023)
- We gratefully acknowledge the Corporate Data Warehouse manager, Sue Candy, and the National Health Laboratory Services for provision of laboratory test data

Severe immunosuppression and viral failure in adult care among antiretroviral therapy-experienced young people with HIV in the UK

Hibo Asad, Jeannie Collins, Ruth Goodall, Caroline Sabin, Ali Judd

On behalf of the Collaborative HIV Paediatric Study (CHIPS) Steering Committee and the UK Collaborative HIV Cohort (UK CHIC) Steering Committee



Background

- UK has one of the oldest populations with perinatal HIV (PHIV) and increasing numbers are transitioning to adult care
- PHIV+ adolescents and young people are at risk of poor adherence^{1, 2}, disengagement from care³, co-morbidity and mortality^{4, 5}
- Evidence for worsening clinical outcomes^{6, 7} in adult care vs paediatric care, but some have small sample sizes

Aim

- To assess the cumulative incidence and predictors of **severe immunosuppression** and **viral failure** in young people with PHIV post-transfer

1 Kim et al, *AIDS* 2014; 2 Ryscavage et al, *J Acquir Immune Defic Syndr* 2011; 3 Rice et al, *Sex Transm Dis* 2011; 4 Fish et al, *HIV Medicine* 2014;

5 Lowenthal et al, *Lancet Infect Dis*; 6 Kakkar et al, *BMC Pediatrics* 2016; 7 Weijnsfeld et al, *Clin Infect Dis* 2016

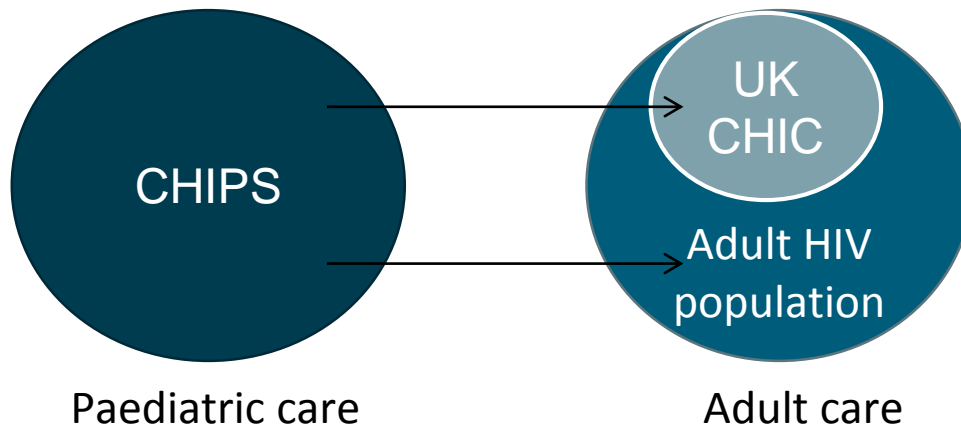
Study population

Collaborative HIV Paediatric Study (CHIPS)

Follows up children diagnosed with HIV <16 years receiving care from paediatric HIV clinics in the UK and Ireland.

UK Collaborative HIV Cohort (UK CHIC) Study

Follows up adults with HIV aged ≥ 16 years attending UK CHIC-participating HIV clinics.



Data linkage methods

Inclusion criteria for linkage:

- CHIPS: aged ≥ 13 years by 01 April 2017 and received paediatric care in the UK
- UK CHIC: aged < 40 years by 01 April 2017

Data linkage:

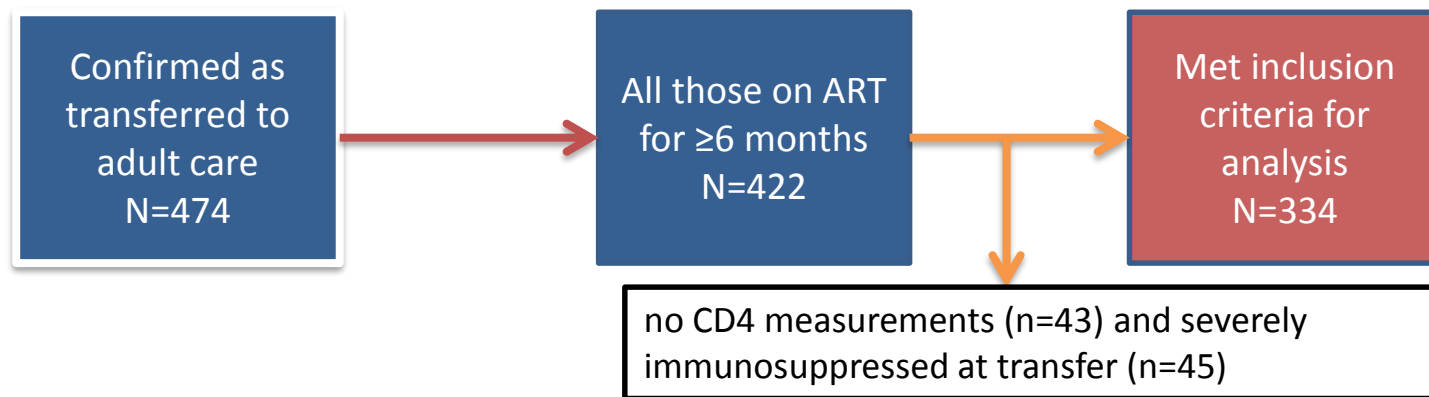
Multi-step process using combination of identifying variables:

- date of birth
- sex
- soundex (alpha-numeric code of patient's surname)
- patient hospital number
- clinic name
- initials



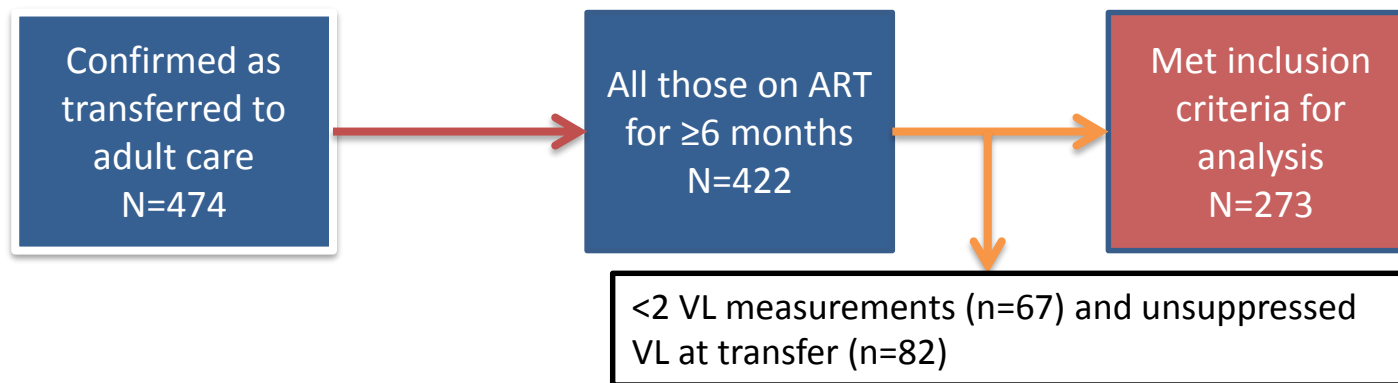
Inclusion criteria for severe immunosuppression analysis

- Inclusion criteria for analysis:
 - ≥ 1 CD4 measurements in adult care
 - CD4 count ≥ 200 cells/mm³ at transfer
 - On ART for ≥ 6 months by transfer
- Time to event analysis (severe immunosuppression, defined as first CD4 < 200 cells/mm³)



Inclusion criteria for viral failure analysis

- Inclusion criteria for analysis:
 - ≥ 2 VL measurements in adult care
 - VL < 400 at transfer
 - On ART for ≥ 6 months by transfer
- Time to event analysis (viral failure, defined as 2 consecutive VL > 400 copies/ml)



Statistical methods

For CD4 and VL model (separately):

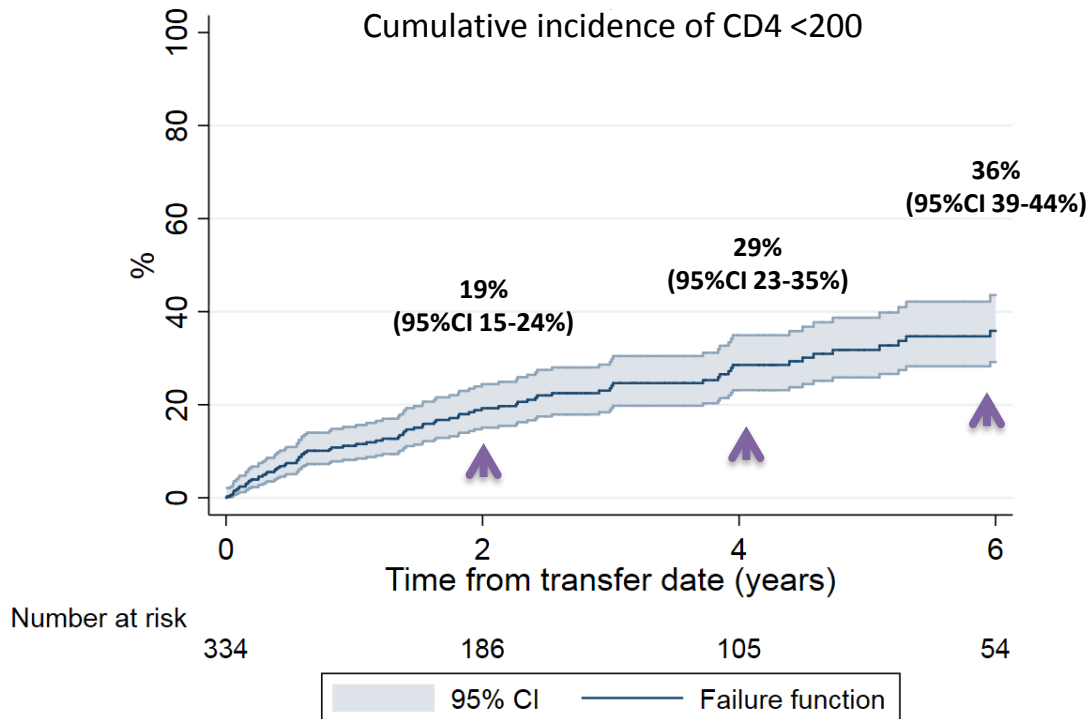
- Cox regression using step-wise backward elimination, with exit probability $p=0.2$
- Model included:
 - ***A priori***: gender, ethnicity and age at transfer
 - ***Demographic***: place of birth
 - ***Clinical variables***: CD4 and viral status at start of ART and last paediatric visit, first ART regimen, ART duration
 - ***Transfer variables***: year of transfer, gap in care between paediatric and adult care

Overall characteristics of all

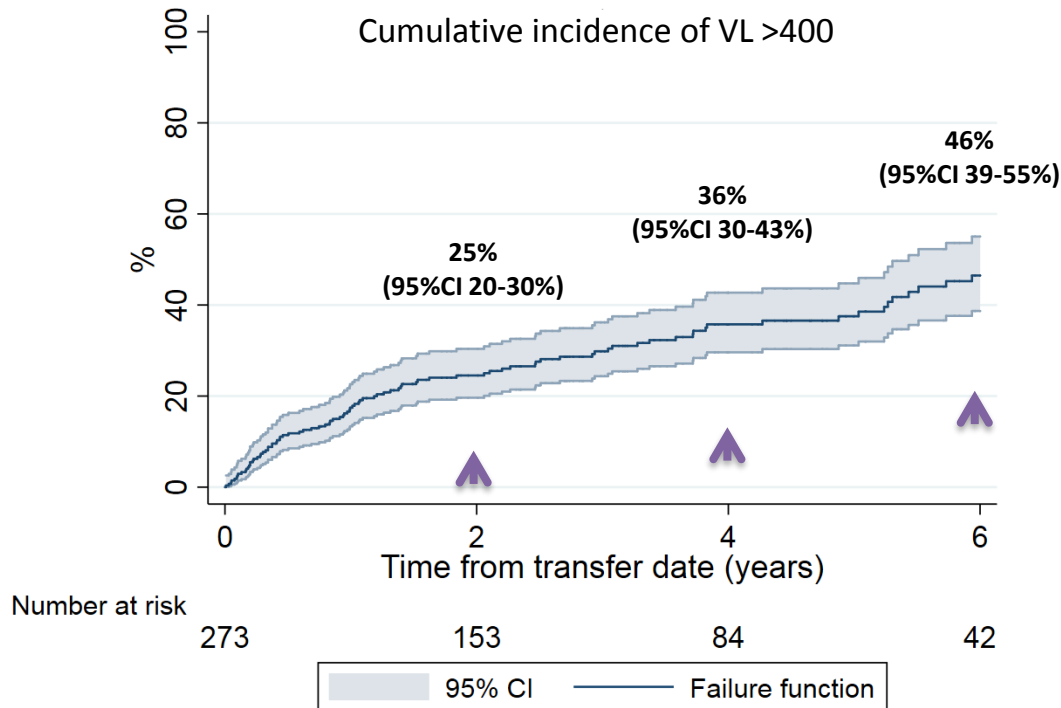
Characteristics (n=422)	N (%)
Female	205 (49)
Black African/Caribbean	339 (82)
Born abroad	248 (60)

Characteristics (n=422)	Last visit in paediatric care	Last visit in adult care
	N (%) or median [IQR]	
Age, years	18 [17, 19]	21 [20, 24]
CD4 count, cells/mm ³	480 [278, 672]	510 [293, 720]
Viral suppression (≤ 400 copies/ml)	275 (65)	291 (73)
Follow-up duration, years	12 [8, 16]	3 [1, 6]
Gap between paediatric and adult care, months	3 [2, 6]	
Deaths in adult care	14 (3)	

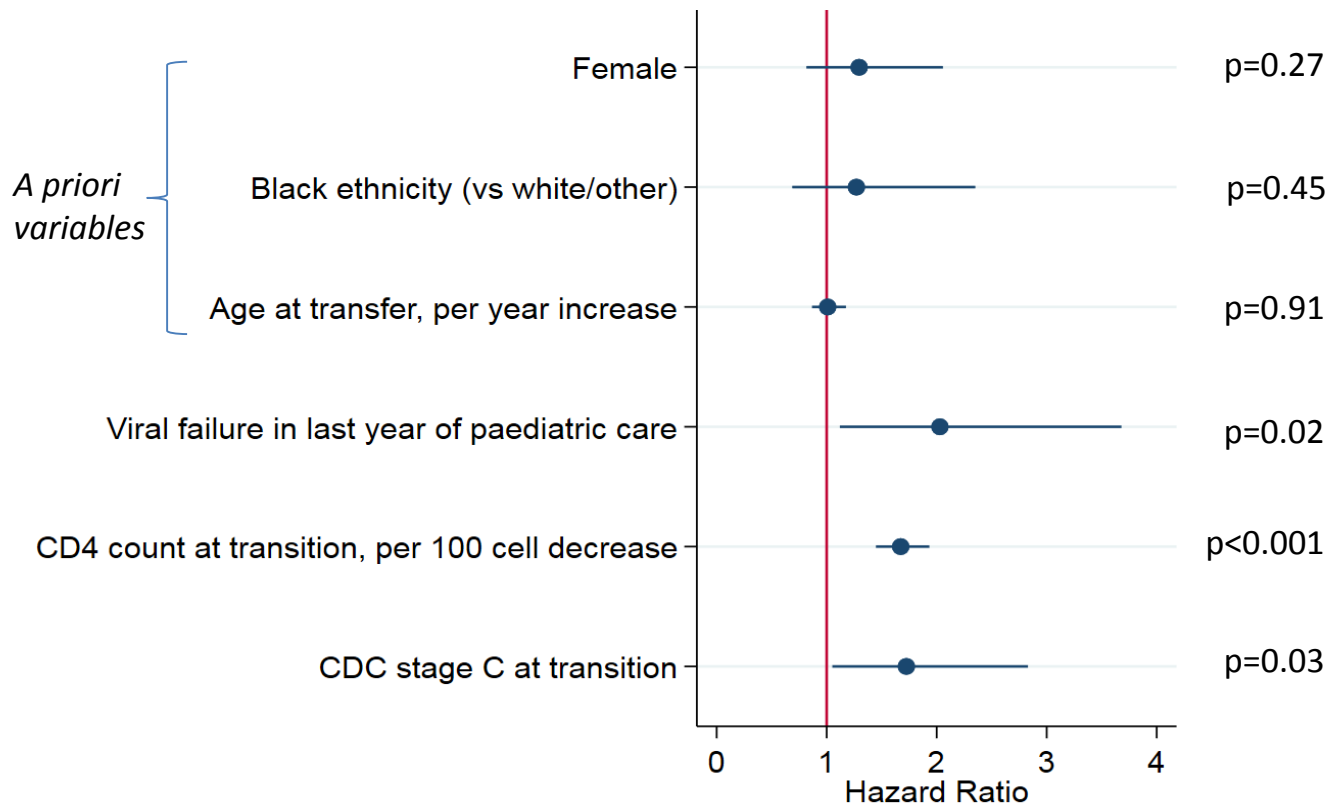
Severe immunosuppression in adult care



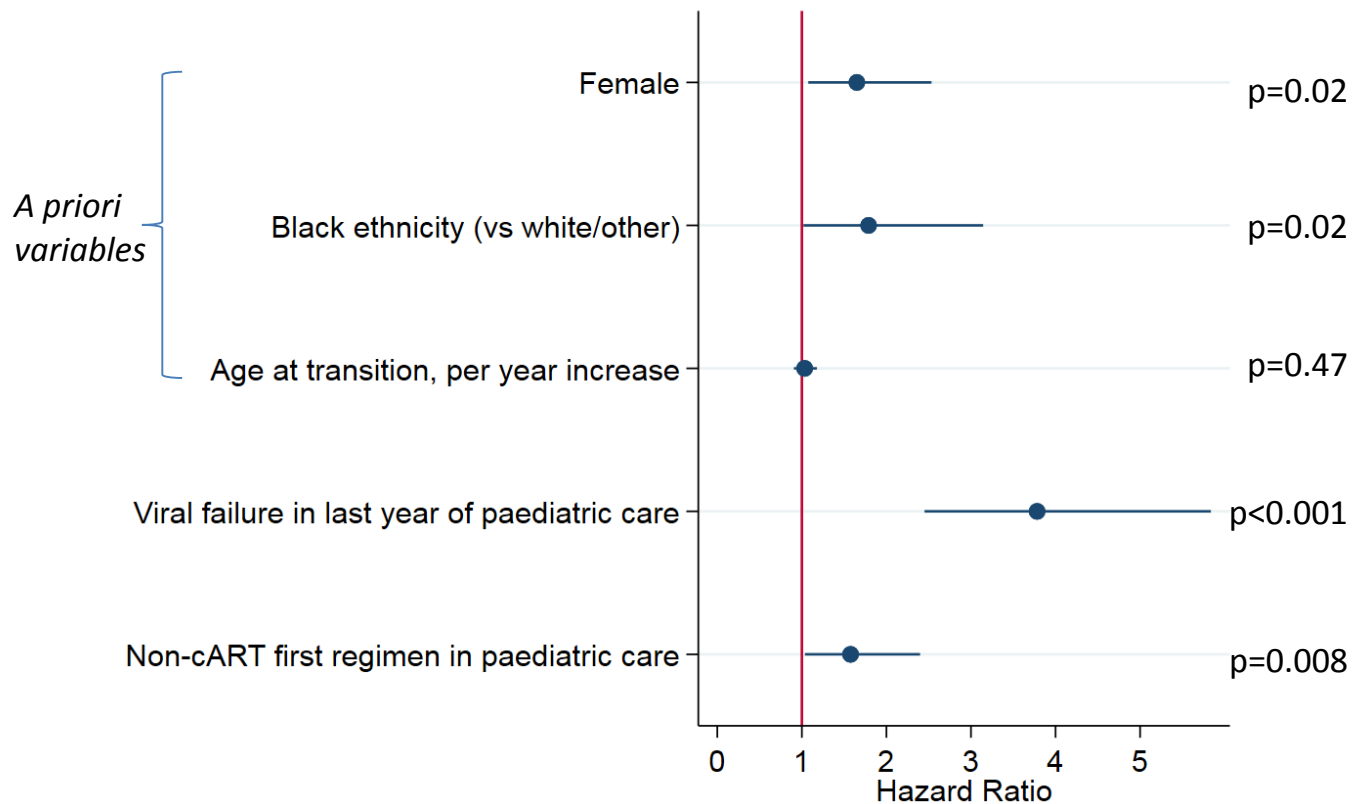
Viral failure in adult care



Predictors of severe immunosuppression in adult care



Predictors of viral failure in adult care



Summary

- Over 4 years of follow-up in adult care, among all those on treatment and with good CD4 or VL status at transfer, a quarter and one-third experienced severe immunosuppression or viral failure in adult care, respectively
- Those with poorer CD4 in paediatric care had higher risk of poor CD4 in adult care
- Patients with unsuppressed VL or initiated on a non-cART regimen were at higher risk of viral failure post-transition
- Results suggest that clinics may wish to focus additional resources in adult care on patients with pre-existing problems in paediatric care

Acknowledgements

I would like to thank:

My supervisors: Ali Judd, Jeannie Collins, Ruth Goodall and Caroline Sabin

My funder: NIHR HPRU

CHIPS Steering Committee: Alasdair Bamford, Karina Butler, Katja Doerholt, Caroline Foster, Di Gibb, Nigel Klein, Hermione Lyall (Chair), Paddy McMaster, Katia Prime, Andrew Riordan, Fiona Shackley, Delane Shingadia, Sharon Storey, Gareth Tudor-Williams, Anna Turkova, Steve Welch.

UK CHIC Steering Committee: Jonathan Ainsworth, Sris Allan, Jane Anderson, Abdel Babiker, David Chadwick, Duncan Churchill, Valerie Delpech, David Dunn, Ashini Fox, Brian Gazzard, Richard Gilson, Mark Gompels, Phillip Hay, Teresa Hill, Margaret Johnson, Sophie Jose, Stephen Kegg, Clifford Leen, Fabiola Martin, Dushyant Mital, Mark Nelson, Chloe Orkin, Adrian Palfreeman, Andrew Phillips, Deenan Pillay, Ashley Price, Jillian Pritchard, Frank Post, Caroline Sabin, Achim Schwenk, Anjum Tariq, Roy Trelvelion, Andrew Ustianowski, John Walsh.

HPRU Steering Committee: Caroline Sabin (Director), Antony Nardone (PHE Lead), Catherine Mercer, Gwenda Hughes, Jackie Cassell, Greta Rait, Sema Mandal, Samreen Ijaz, Tim Rhodes, Kholoud Porter, William Rosenberg.

HR update

Carole Booth
HR Manager

Mid Year Review 2018

Leavers: 18 leavers, 9 exit interviews held (50%) in H1 2018. (compared to 34 leavers; 25 exit interviews held (73%) in 2017)

Recognition & Engagement:

- a) **Senior promotions** (to UCL Grades 9 & 10) – 5 successful 2017/8.
- b) **Academic & Research promotions** (to UCL Grades 7 & 8) – 2 successful applications for 2017/8.
- c) **UCL Accelerated Increments** – 5 successful applications submitted in June; (5 successful applications submitted in Nov 2017).
- d) **MRC Special Award Scheme** - 5 applications submitted & awaiting approval (16 successful applications relating to achievements in 2015 & 2016).
- e) **MRC A to B Accelerated moves** - 2 successful applications submitted in Nov 2017.

Recruitment: 31 different role types advertised & 30 recruited with 5 still ongoing; 653 candidates applied. Interview selections managed and new hires on-boarded.



Inductions: Individual inductions held for 30 new joiners (HR, Facilities, IS).

MRC CTU Training committee facilitated Unit induction – held 29 June

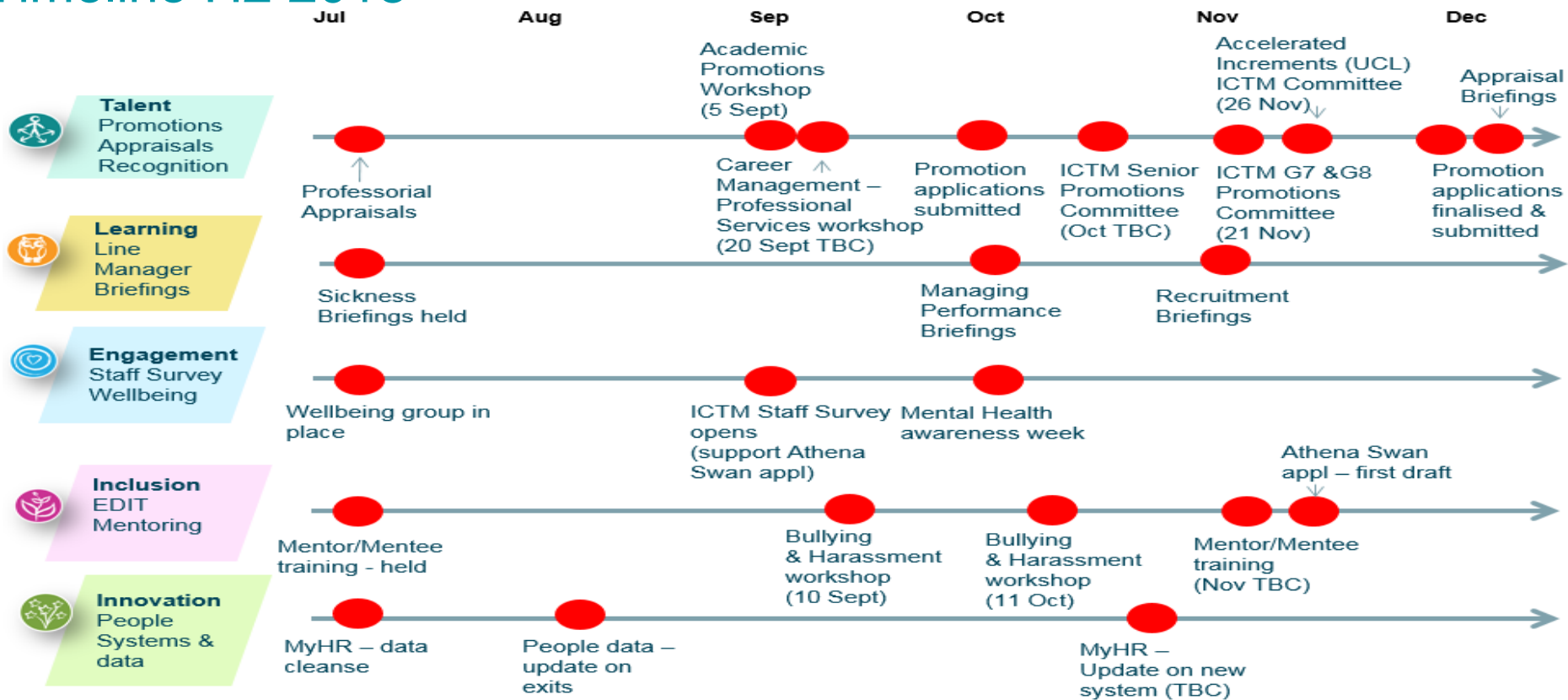
Appraisals: 77% completed for performance year ending 2017.

Appraisal briefings held with over 60 participants (content informed by the appraisal survey held in H1 2017).

Flexible working: new arrangements in place for 19 employees during H1 2018.

Line manager briefings ('Lunch & Learns') x 2 held on managing sickness.

Timeline H2 2018



General Data Principles Regulation update

Lailaa Carr

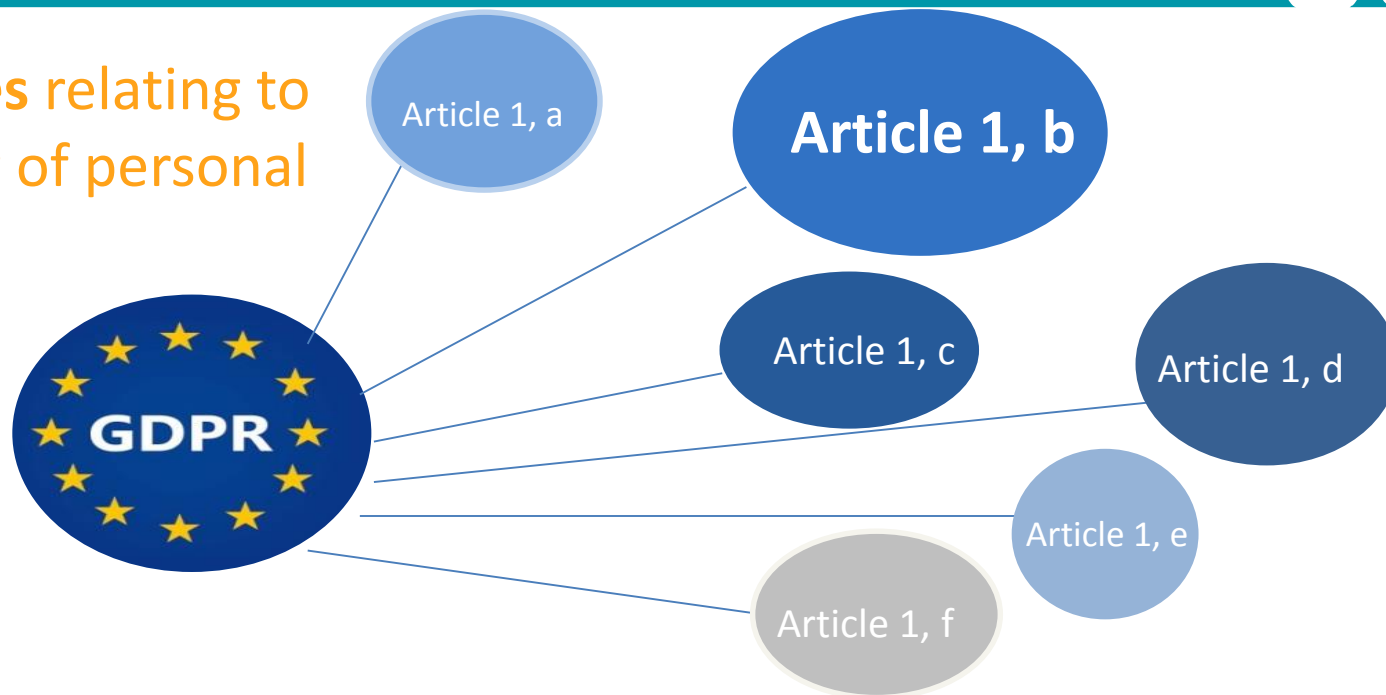
Contracts Manager



GDPR - LAWFULNESS OF PROCESSING: 6 MAIN LEGAL GROUNDS

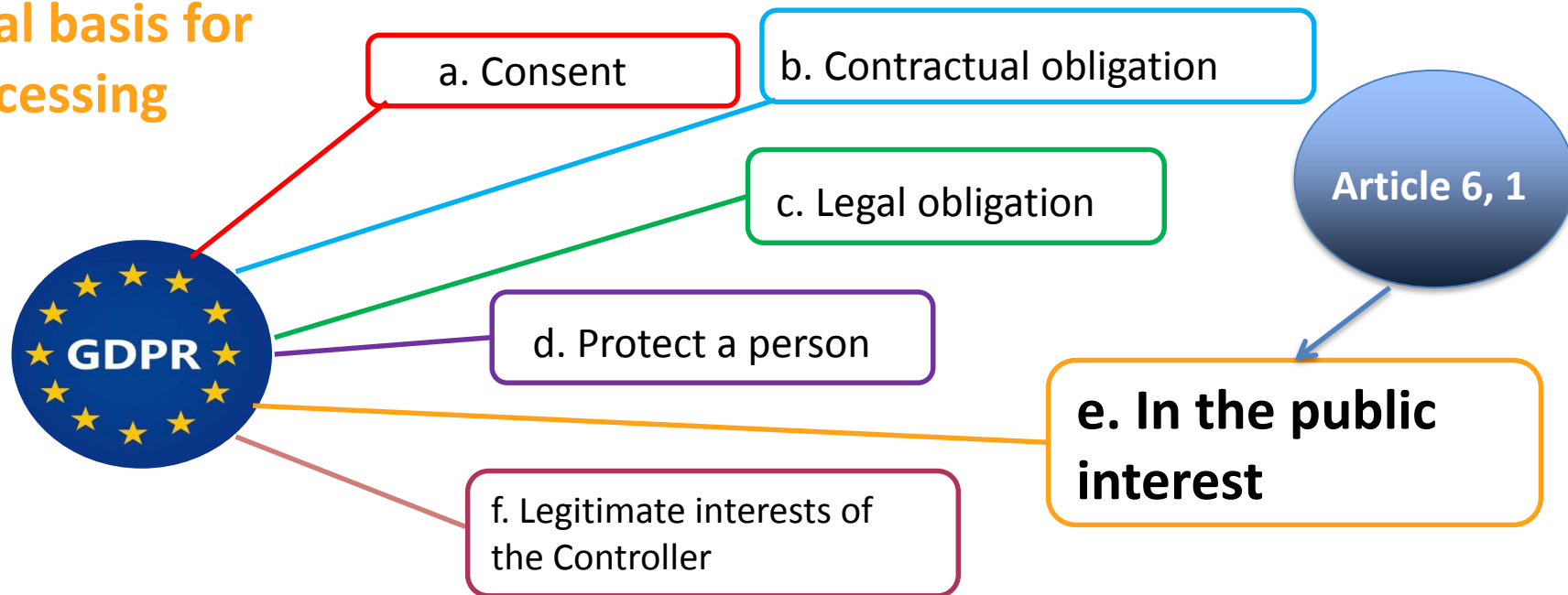


6 Principles relating to processing of personal data



For research, we use **Article 1, b**: “.....**in the public interest**.....”. This assures participants that their personal data is being used for the public good.

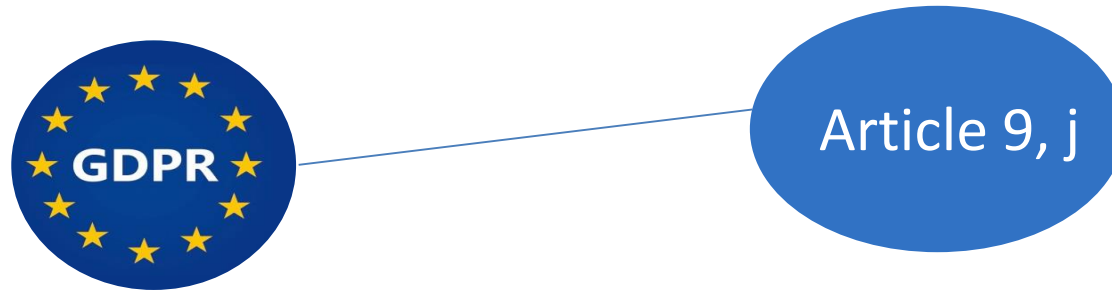
Legal basis for processing



Our legal basis for processing is under **Article 6, 1 (e)**: “processing is necessary for the performance of a **task carried out in the public interest**”.

Processing special categories – additional condition

When processing special categories of personal data, like health data for research, you need an additional condition; Special categories of personal data **Article 9, j** **“Necessary for scientific or historical research purposes” in line with safeguards**”.



Using **“task in the public interest or “legitimate interest along with “necessary for scientific research in line with safeguards”** for more sensitive data builds trust that personal data is being used for the public good, legitimate research and that personal data will be protected.

Consent - to satisfy other pieces of law e.g. Human Tissue Act, Clinical Trials Regulations, and the common law of confidentiality.

Consent - appropriately informed and freely given

GDPR

Consent- gives control on how its used, i.e., the right to opt out

Consent – ethical cornerstone of research

CONSENT IS KING

Transparent, lawful and fair

Consent - from individuals who are able to make this decision themselves

Processing of special category personal data falls under **Article 9: 2, (j)** “**in the public interest.... in accordance with safeguards**” such as;

SOPs, having Agreements,
following standards / practices

Obtaining research
ethics approval

Only processing what is
necessary / relevant

Appropriate levels of security,
IT, encryption,

Data minimisation
(pseudonymisation)



True or false?

- a. “You must have consent to process personal data”.
- b. “Participants need to be re-consented every 1 – 2 years”.
- c. “GDPR stops us disclosing or sharing our data with collaborators through Open Access”.
- d. “Ethics approval gives us our legal basis”

- d. “GDPR will stop research nurses from identifying potential participants”.
- e. “GDPR means I have to delete my research database”.
- f. I don’t need to worry about GDPR, I only ever see data where the names have been removed”.
- g. “IP addresses, cookies, device ID and web data is not personal data”



All that false, non-
research, un-consented
data on muggles from
16 AD to 2017

Examples of transparency

Patient information sheet, posters

Displaying information in waiting rooms

Links to Study websites

Privacy notices to include how data is used to support research

Other study documents or materials

Information should be clear, concise and easy to understand; no jargon



GDPR & Data Protection Act 2018 – comparisons

- **GDPR:** Processed **lawfully, fairly** and in a **transparent** manner;
- **DPA:** **Lawful, fair and transparent**
- **GDPR:** Collected for a **specified** purpose, **explicit** and **legitimate**;
- **DPA:** Purpose must be **specified, explicit** and **legitimate**
- **GDPR:** **Adequate, relevant, limited** to what is necessary;
- **DPA:** **Adequate, relevant** and **not excessive**
- **GDPR:** Kept in a form which **permits identification** of data subjects for **no longer than is necessary**;
- **DPA:** **Accurate** and kept **up to date**
- **GDPR:** Processed in a manner that ensures **appropriate security** of personal data
- **DPA:** Includes **appropriate security** measures such as passwords, anonymisation, pseudonymisation, SOPs, IT, encryption, approvals etc.

Underlying message Don't panic girls!



Our role and partners

We regularly provide information and feedback to the MRC Regulatory Support Centre (RSC) on the questions and queries you have on GDPR and the Data Protection Act, and in turn they feedback to us.

The RSC seeks answers to these directly from the ICO and the HRA. Speaking to us is the quickest and best way to gain the **right** answers from the **right** sources.

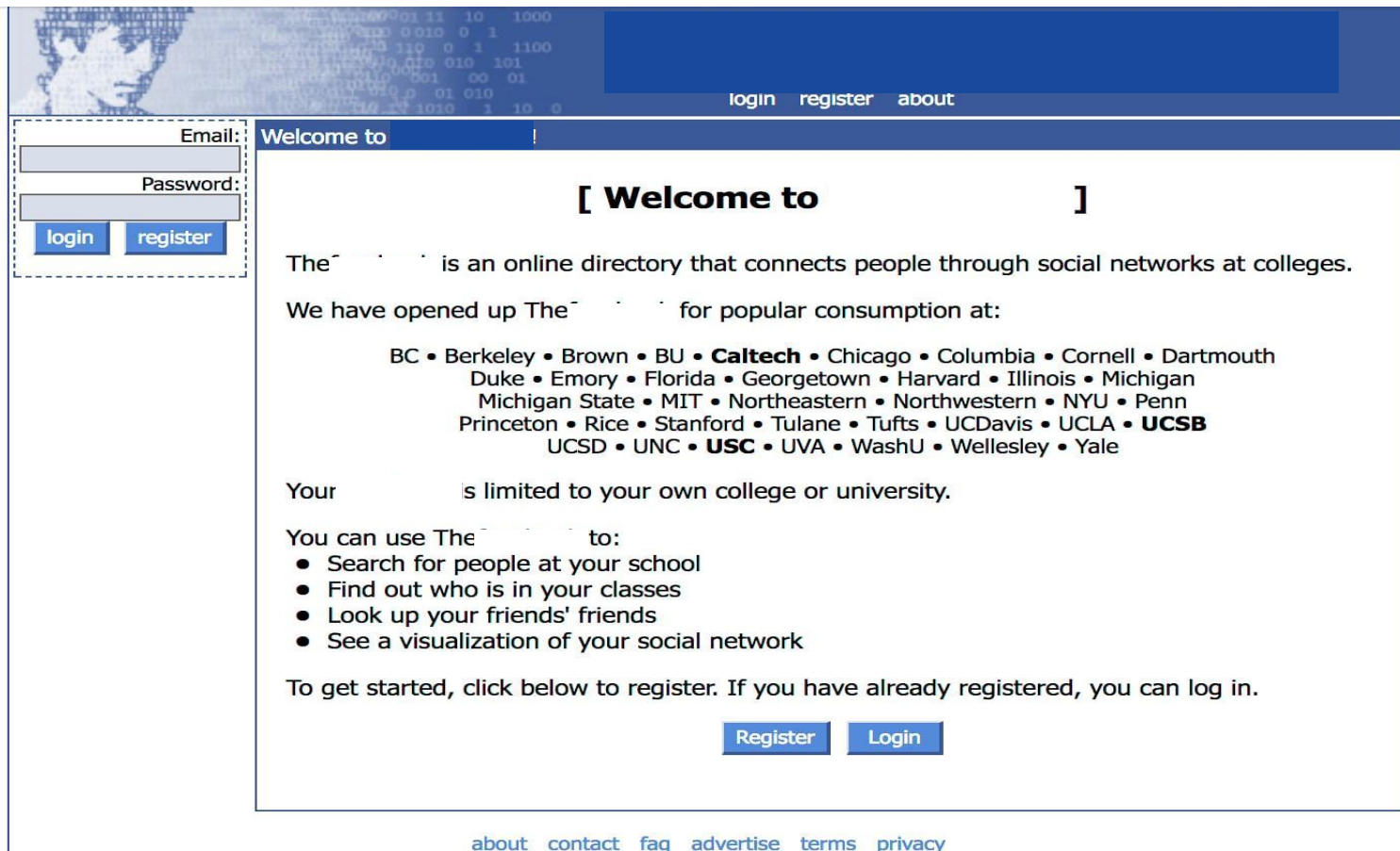
ICTM contracts is developing ‘**Bitesize GDPR and DPA**’ training sessions for all, dates to be published soon, we also plan to provide;

mini booklets, leaflets

online resource materials via the intranet and the ICTM website.

If you need help in the meantime come and see us we’re at desks 2095 and 2096 or, Email: ictm.contracts@ucl.ac.uk



A screenshot of a website's login and registration page. The page has a dark blue header with a navigation menu containing 'login', 'register', and 'about'. On the left side, there is a login form with fields for 'Email:' and 'Password:', and two buttons labeled 'login' and 'register'. The main content area is white with a dark blue border. It features a large heading '[Welcome to]' and a paragraph of introductory text. Below this, there is a list of university names, with 'Caltech' and 'UCSB' in bold. At the bottom of the main content area, there are two buttons labeled 'Register' and 'Login'. A footer at the very bottom contains a list of links: 'about', 'contact', 'faq', 'advertise', 'terms', and 'privacy'.

login register about

Email:

Password:

login register

Welcome to

[Welcome to]

The [] is an online directory that connects people through social networks at colleges. We have opened up The [] for popular consumption at:

BC • Berkeley • Brown • BU • **Caltech** • Chicago • Columbia • Cornell • Dartmouth
Duke • Emory • Florida • Georgetown • Harvard • Illinois • Michigan
Michigan State • MIT • Northeastern • Northwestern • NYU • Penn
Princeton • Rice • Stanford • Tulane • Tufts • UC Davis • UCLA • **UCSB**
UCSD • UNC • **USC** • UVA • WashU • Wellesley • Yale

Your [] is limited to your own college or university.

You can use The [] to:

- Search for people at your school
- Find out who is in your classes
- Look up your friends' friends
- See a visualization of your social network

To get started, click below to register. If you have already registered, you can log in.

Register Login

about contact faq advertise terms privacy


Recognise me now?

facebook

Email or Phone Password Log In

Keep me logged in [Forgot your password?](#)

Facebook helps you connect and share with the people in your life.

A stylized world map with several orange person icons placed across different continents. Dotted lines connect these icons, representing a global network of users.

Sign Up

It's free and always will be.

First Name Last Name

Your Email

Re-enter Email

New Password

Birthday

Month Day Year [Why do I need to provide my birthday?](#)

Email addresses - The value of privacy

“If I’ve learned one thing from Mark Zuckerberg it’s that the most valuable knowledge about another person comes from learning things about them that they wouldn’t tell you themselves”.

Mark Zuckerberg’s **email address** is not known by anyone except his most closest and trusted contacts. Protecting his personal information.....



Mark Zuckerberg likes this!
Facebook™ ©

Fair

Lawful

GDPR & Data Protection Act

Transparent



ICTM Facilities Update

Rachel Martino

Unit Manager, MRC CTU

July 2018

Key Items

ICTM Accommodation Committee

90HH Formal 6mo Review

90HH Utilisation space

Business Continuity

ICTM Accommodation Committee

Project Board > ICTM AC

Desk Zone leads – **do you know ours?**

Key Remit:

- ✓ Desk utilisation optimisation
- ✓ Desk allocation
- ✓ Chronic facilities issues (not day-to-day)

90HH Formal 6mo Review

Outputs include:

- Investigation into AV for 1st floor meeting rooms
- Formal meeting to address snagging summer 2018
- Fire safety on 1st floor to be addressed
- Review of space 2020

HOT TOPIC - Utilisation

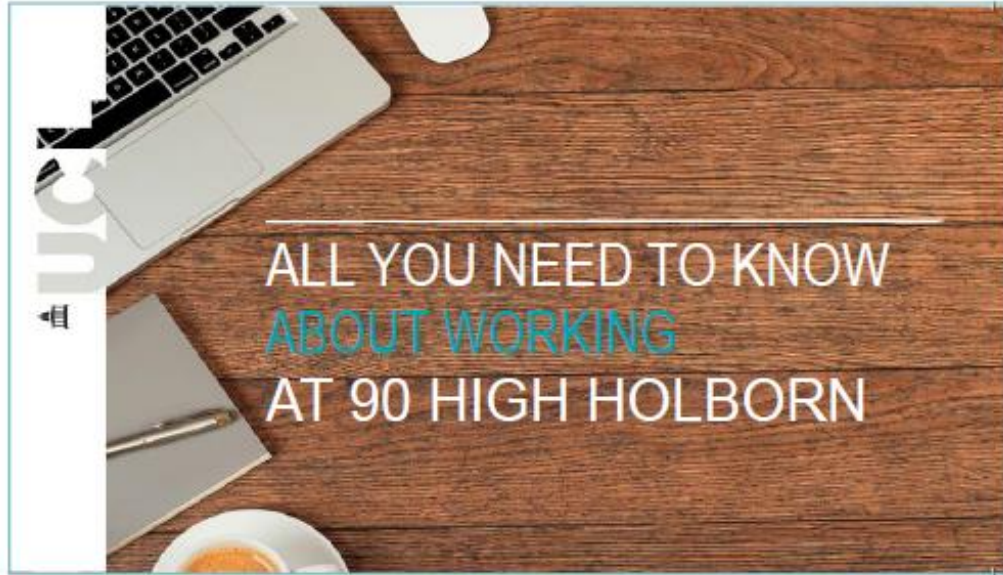
We need to improve:

- Move towards optimal utilisation
- More agile working practices where able**
- Make full use of technology such as SKYPE for Business

Supporting Utilisation

To help...

- Forecasting & planning at ACM
- Bespoke systems for teams (ie. Red cards)
- Improving signage on hot desks
- Lynda.com for SKYPE for Business
- More training for SKYPE for Business & A/V in meeting rooms
- Headsets available to order



Remember me?

- 1 per desk
- Stays on desk
- Take a peek!

We need your help...

Keep it clean – desks, toilets, kitchen, meeting rooms, etc.

Food – keep in pest-proof containers

Supplies – only order what you have room to store

Post & couriers – collect post & announce deliveries

Guests – greet, safety & let them out!

Meeting rooms – clean up & don't unplug HDMI

Business Continuity

Have you ever experienced Business Continuity in action?

Business Continuity

A plan to be used in the event of any **major incident or disaster**, which impacts the normal undertaking of our business with the aim to **minimise disruption and maximise safety**.

What you need to know!

Role of individual

- How to stay safe
- How to contact your Line Manager & team
- How to connect to email
- Plan in advance
- Always have your badges on you!

Testing, testing...

Business Continuity Team

- Working to v2 BCP
- Planning tests for 2018
- SMS cascade test for ICTM
- Lunch & learn session for more BC information

SMS contact for BCP

How & why?

- Duty of care & your safety
- Collection of data
- Use of your number
- Security & access
- How testing works

Questions?