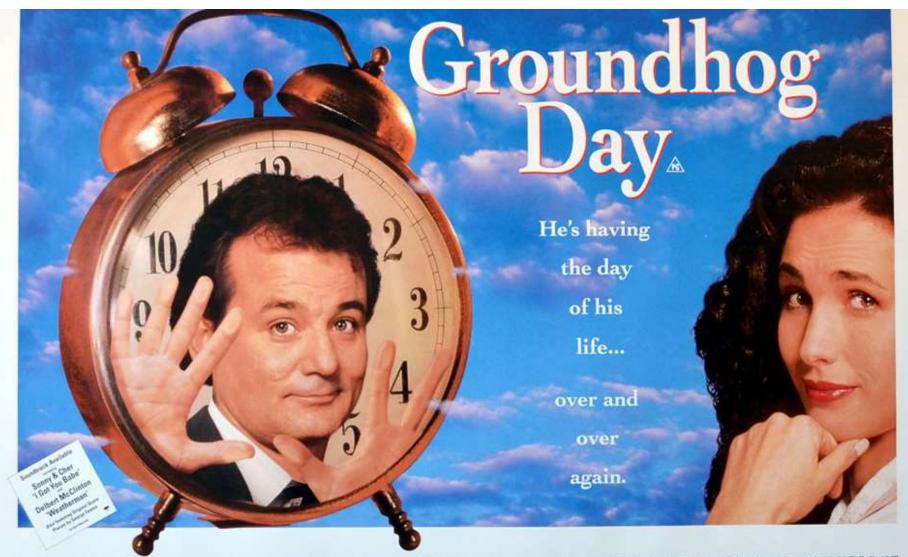


UKCRC Tissue Directory and Coordination Centre

Phil Quinlan

Advanced Data Analysis Centre

University of Nottingham

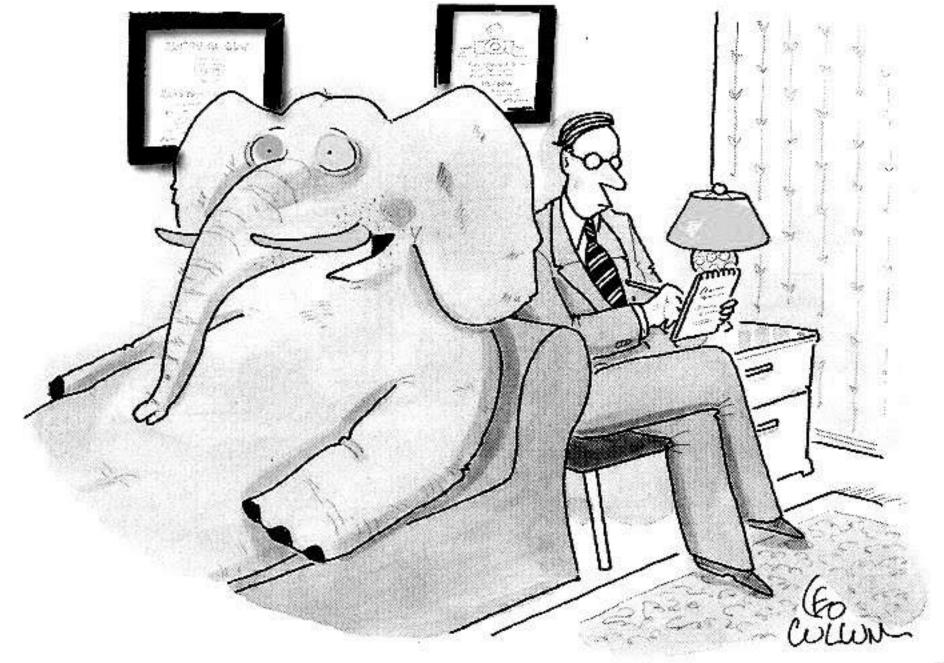


COLUMBIA DICTUDES DECENTS: A TREVOR ALBERT PRODUCTION A HAROLD RAMIS FILM. RILL MURRAY ANDIE MACDOWELL. "GROUNDHOG DAY"

This is not just another one

The tissue directory – aims, problems, solutions





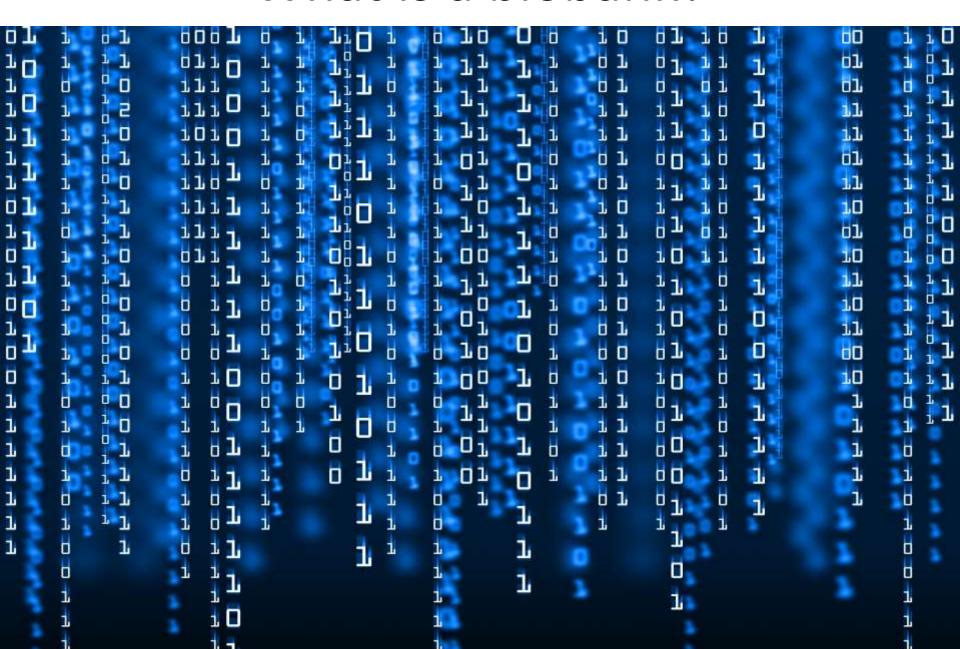
"Im right there in the room, and no one even acknowledges me."







What is a biobank?



Why do we need a directory?

RESEARCH ARTICLE

Open Access

Critical research gaps and translational priorities for the successful prevention and treatment of breast cancer

Suzanne A Eccles^{17*}, Eric O Aboagye¹, Simak Ali¹, Annie S Anderson², Jo Armes⁷, Fedor Berditchevski⁴, Jeremy P Blaydes³, Keith Brennan⁵, Nicola J Brown⁶, Helen E Bryant⁶, Nigel J Bundred⁵, Joy M Burchell⁷, Anna M Campbell², Jason S Carroll⁹, Robert B Clarke⁵, Charlotte E Coles³⁴, Gary JR Cook⁷, Angela Cox⁶, Nicola J Curtin¹⁰, Lodewijk V Dekker¹¹, Isabel dos Santos Silva¹², Stephen W Duffy¹³, Douglas F Easton⁹, Diana M Eccles³, Dylan R Edwards¹⁵, Joanne Edwards¹⁴, D Gareth Evans⁵, Deborah F Fenlon³, James M Flanagan¹, Claire Foster³, William M Gallagher¹⁶, Montserrat Garcia-Closas¹⁷, Julia M W Gee¹⁸, Andy J Gescher²⁸, Vicky Goh⁷, Ashley M Groves⁸, Amanda J Harvey³³, Michelle Harvie⁵, Bryan T Hennessy²⁰, Stephen Hiscox¹⁸, Ingunn Holen⁶, Sacha J Howell⁵, Anthony Howell⁵, Gill Hubbard²¹, Nick Hulbert-Williams²², Myra S Hunter⁷, Bharat Jasani¹⁸, Louise J Jones¹³, Timothy J Key²³, Cliona C Kirwan⁵, Anthony Kong²³, Ian H Kunkler²⁴, Simon P Langdon²⁴, Martin O Leach¹⁷, David J Mann¹, John F Marshall¹³, Lesley Ann Martin¹⁷, Stewart G Martin¹¹, Jennifer E Macdougall²⁵, David W Miles⁷, William R Miller²⁴, Joanna R Morris⁴, Sue M Moss¹³, Paul Mullan²⁶, Rachel Natrajan¹⁷, James PB O'Connor⁵, Rosemary O'Connor²⁷, Carlo Palmieri³¹, Paul D P Pharoah⁹, Emad A Rakha¹¹, Elizabeth Reed²⁹, Simon P Robinson¹⁷, Erik Sahai³², John M Saxton¹⁵, Peter Schmid³⁰, Matthew J Smalley¹⁸, Valerie Speirs¹⁹, Robert Stein⁸, John Stingl⁹, Charles H Streuli⁵, Andrew N J Tutt⁷, Galina Velikova¹⁹, Rosemary A Walker²⁸, Christine J Watson⁹, Kaye J Williams⁵, Leonie S Young²⁰ and Alastair M Thompson^{2*}









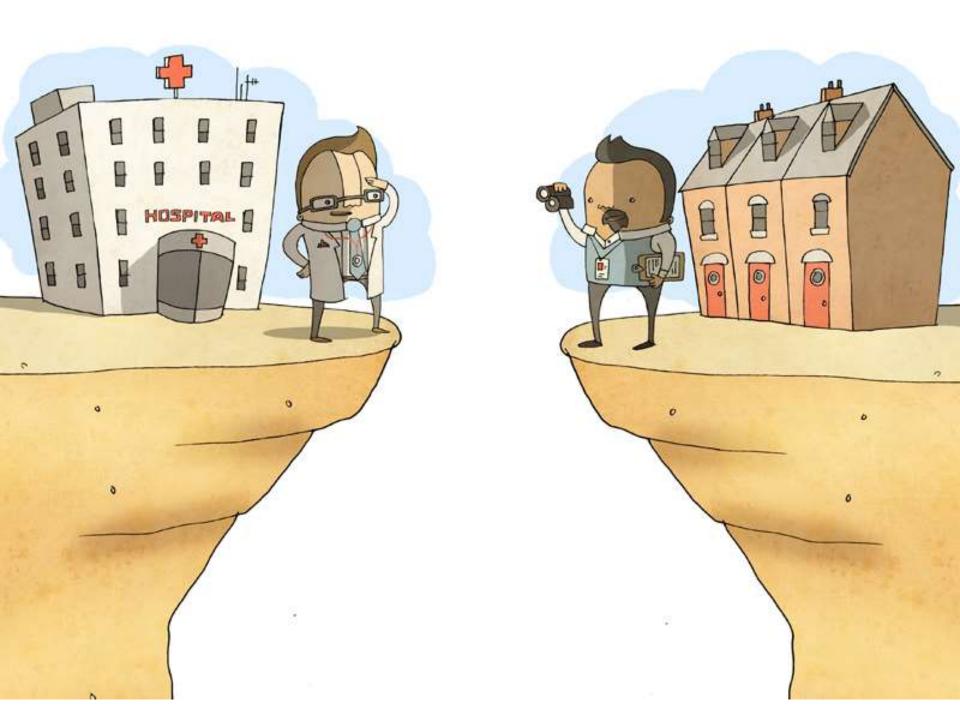




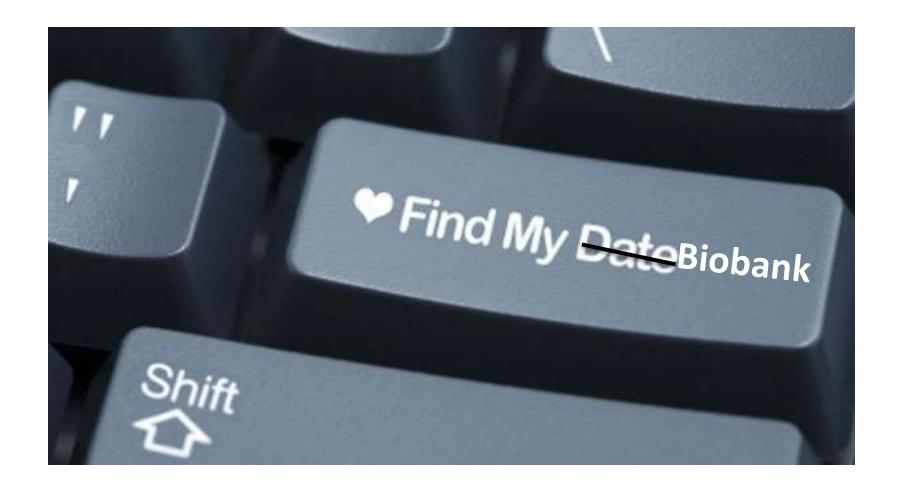








Our Aim?





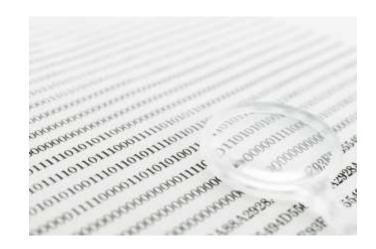
Our problems?









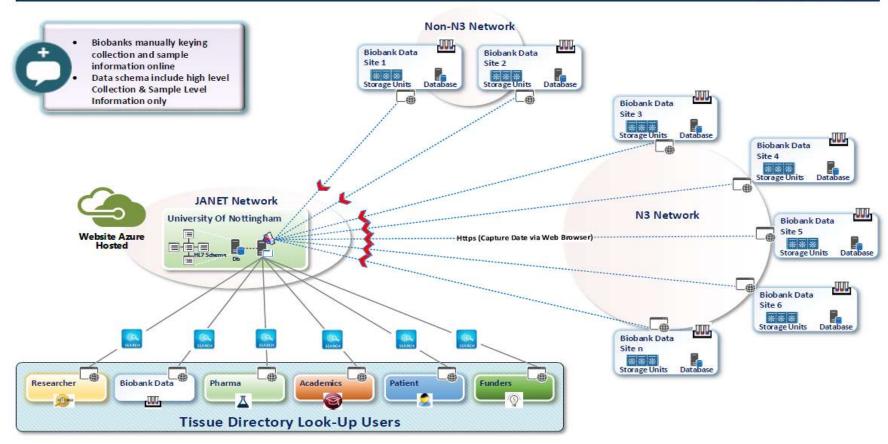




Biobank Web Based Directory Lookup

Phase 1 - To Be Landscape (Biobanks Keying Collection & Sample Data Online)





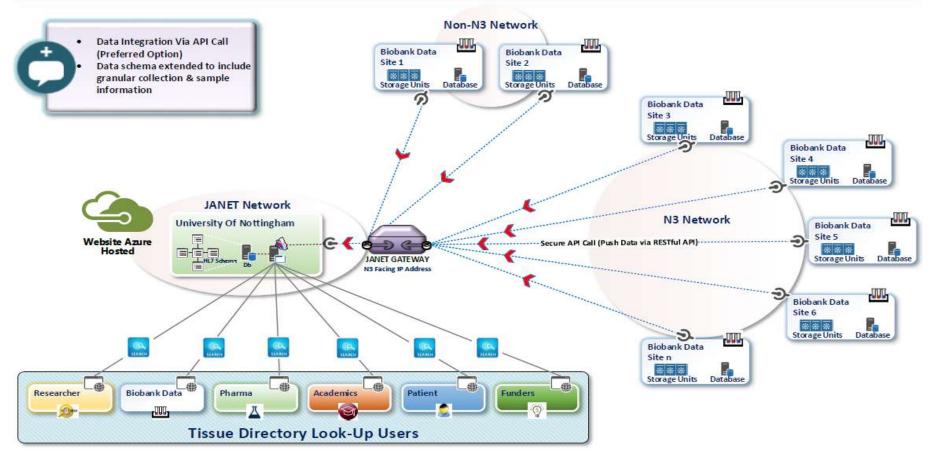
(d) (d)	Biobank Architecture For Phase I And II.vsdx		
Author	Vineet,Chugh	Phase 1 - Data Keyed Online	Wed-02-Sep-2015 11:51



Biobank Web Based Directory Lookup

Phase 2 - To Be Landscape (Biobanks pushing Data via API calls)





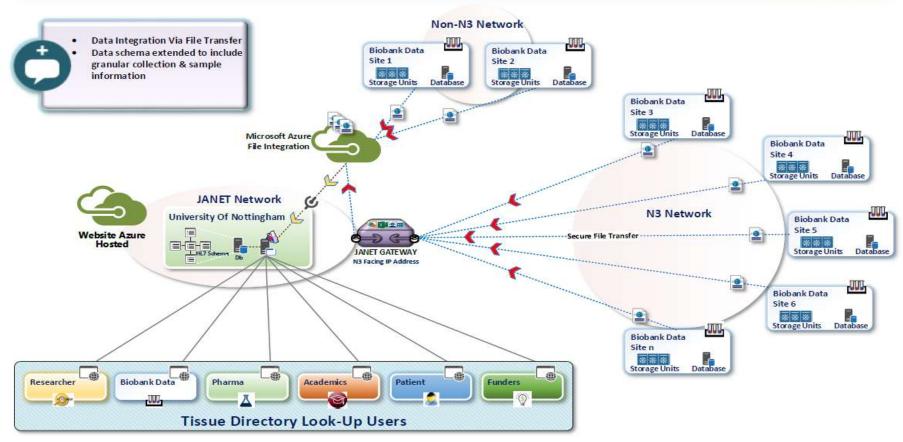
8	Biobank Architecture For Phase I And II.vsdx				
Author	Vineet.Chugh	Phase 2 - Data Push Via API Calls	Wed-02-Sep-2015 11:51		



Biobank Web Based Directory Lookup

Phase 2 - To Be Landscape (Biobanks pushing Data via File transfer)





Biobank Architecture For Phase I And II.vsdx					
Author	Vineet.Chugh	Phase 2 - Data Push Via File Transfer	Wed-02-Sep-2015 11:51		





Interactive Software Infonetica Krishagni





We Need You!

- Funders
- Regulators (HTA, NRS Scotland)
- Ethics Committees
- Biobanks
- Donors
- Software Vendors







We Need You! Funders

Fund support for data within biobanks

Build sufficient data management planning into your review







We Need You! Regulators

Seek robust data management plans

Not using samples is an inappropriate 'use' of samples







Is it ethical to collect samples if samples cannot be used because of insufficient data?







We Need You! Biobanks

Help us understand your current abilities

What datasets are you trying to create?







We Need You! Donors

Work with us on building a research environment that supports research but maintains privacy







Remove the necessary 'optional' extras – data sharing is no longer optional.

Seek consensus on standards in a pre-competitive manner







We Need You!

Phil Quinlan

Advanced Data Analysis Centre University of Nottingham

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Website: https://www.biobankinguk.org/

Advanced Data Analysis Centre

