UNIVERSITY OF LIVERPOOL

The Walton Centre NHS
NHS Foundation Trust

Excellence in Neuroscience

Biobanking: how it works and why it is important?

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TBTC Nurse & AHP Study Day, Birmingham 19th May 2017

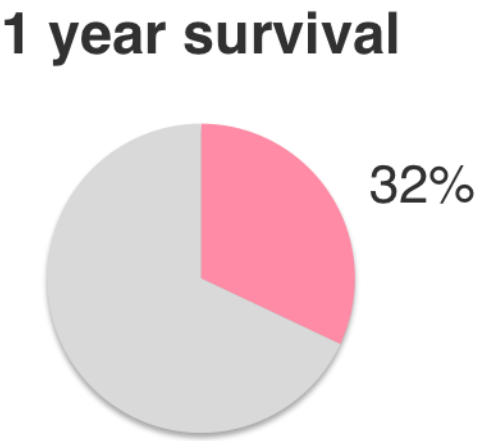
Running order

- Why biobank?
- Biobanking models?
- Requirements for a biobank
- How we do it in Liverpool
- Future of biobanking in the UK

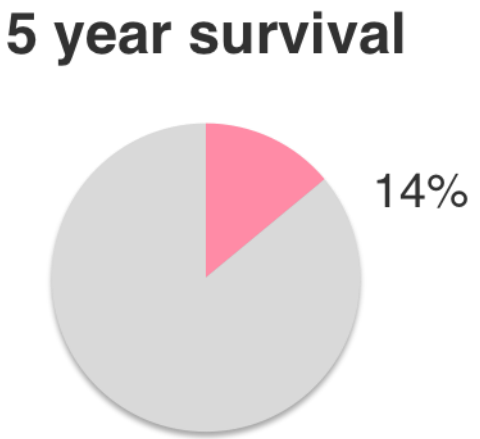
1. Why biobank?

Patient's perspective

- Most prevalent solid tumour in children
- Commonest cause of cancer death in children
- 1/3 cancer patients develop brain mets



- 3rd leading cause of cancer-related death among men between 15 – 54 years
- 4th leading cause of cancer-related death among women between 15 – 34 years



Patient experience of biobanking and the value of research

- My personal experience was brilliant, but I had no prior knowledge
- We're none of us as smart as all of us
- Important to understand and respect everyone's areas of expertise
- Patients want to be involved but it needs to be managed
- Raising awareness is important

meg@ brainstrust
the brain cancer people

“Tissue is the issue”
Human samples in research

- Patients know their samples are important but don't have enough information
- They understand the need to link symptoms to the disease process
- They understand the need to be able to predict the effects of new treatments
- Patients can be a big driver in ensuring their tissue is collected

THE CANCER GENOME ATLAS
National Cancer Institute
National Human Genome Research Institute

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Glioblastoma Multiforme

Last Updated: January 03, 2014

What is glioblastoma multiforme?

Glioblastoma Multiforme (GBM) is a fast-growing type of malignant brain tumor that is the most common brain tumor in adults. In 2010, more than 22,000 Americans were estimated to have been diagnosed and 13,140 were estimated to have died from brain and other nervous system cancers.[1] GBM accounts for about 15 percent of all brain tumors and occurs in adults between the ages of 45 to 70 years.[2] Patients with GBM have a poor prognosis and usually survive less than 15 months following diagnosis. Currently there are no effective long-term treatments for this disease. View additional information on brain tumors.

What have The Cancer Genome Atlas (TCGA) researchers learned about GBM?

Over the course of six years of study and two journal publications, TCGA researchers have:

- Established a new subtype of GBM that affects younger adults and has an increased survival rate. A subset of GBM tumors had specific chemical changes called methylation of a large

Sample Collection Complete	Data Publicly Available
✔	✔

Multimedia

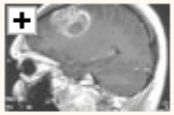


Image: Glioblastoma - MRI

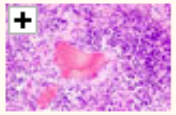


Image: Glioblastoma

Video: Neil Hayes, M.D., M.P.H., Explains TCGA Findings on Glioblastoma (2:51)

But limited clinical annotation

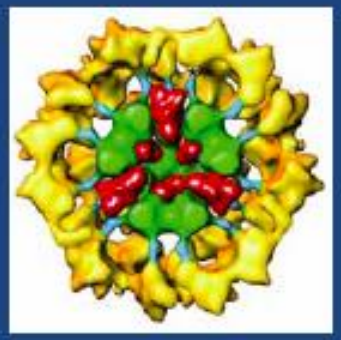
How relevant are the results to routine clinical practice?

GBM subtypes. Knowing a tumor's subtype could help match each patient to the most effective therapies. See more information about TCGA brain tumor subtype studies.

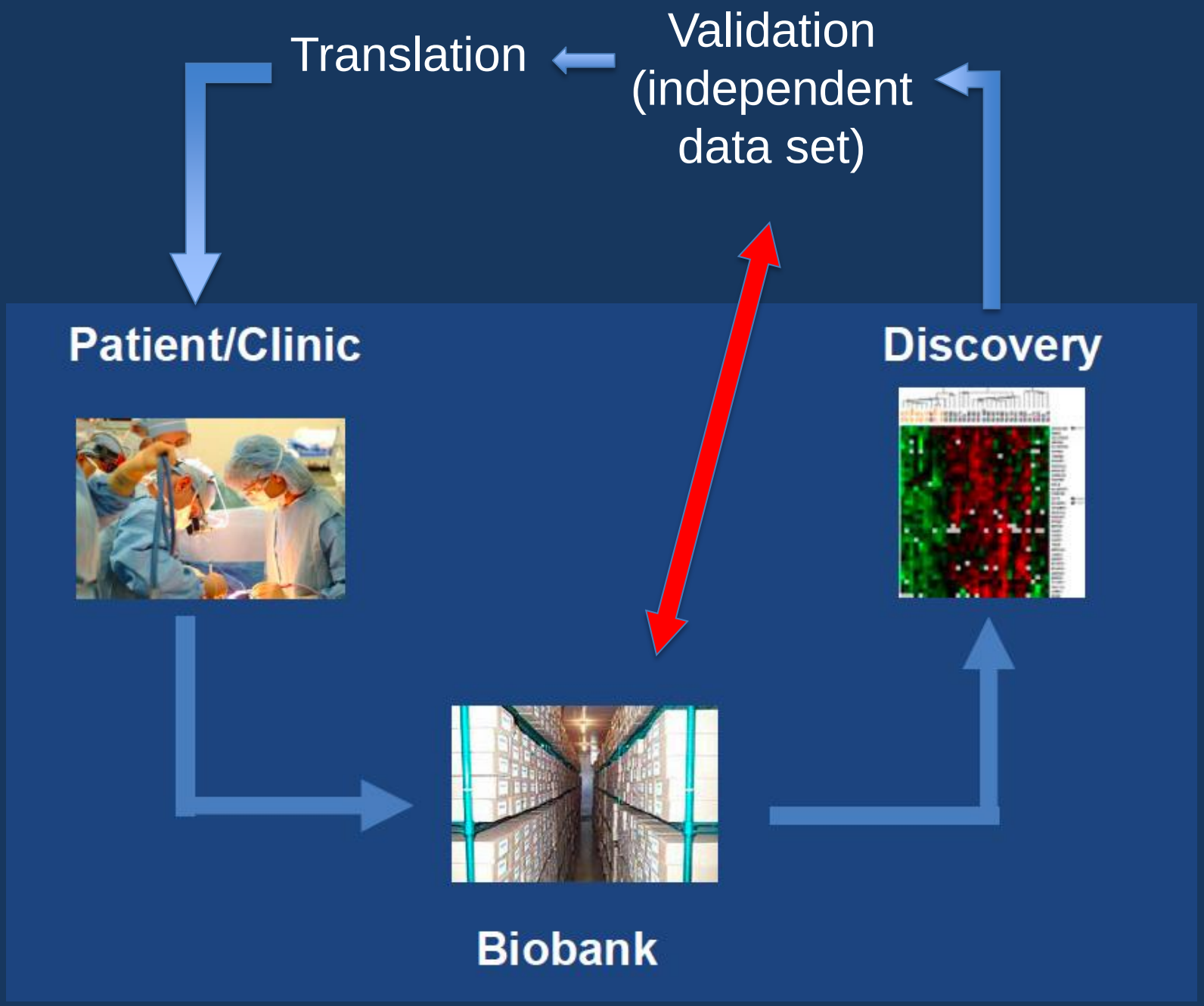
Podcast: Spanish

Beyond genomic - the other ‘omics’

Genomics **Proteomics** **Metabolomics**



All depend on high quality annotated human biospecimens


Translation
Validation (independent data set)
Patient/Clinic
Discovery
Biobank

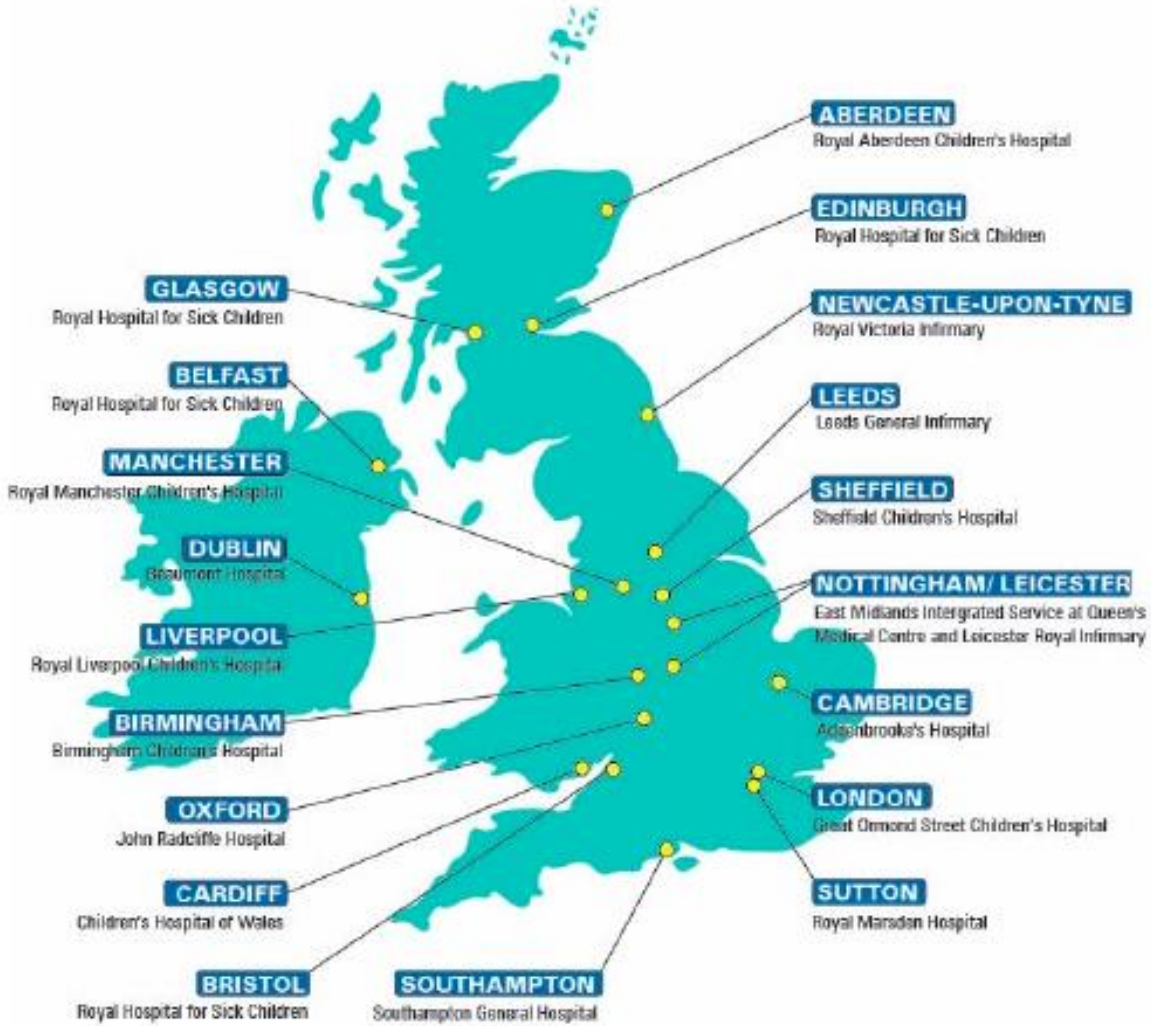
2. Biobanking models

Single national biobank

-versus-

Network of biobanks

The CCLG Tissue Bank is the UK's largest unique collection of tumour, DNA and other tissue samples from childhood cancer patients.



CCLG Tissue Bank

Children's Cancer and Leukaemia Group

40 YEARS SAVING YOUNG LIVES

The CCLG Tissue Bank is the UK's largest unique collection of tumour, DNA and other tissue samples from childhood cancer patients.

Paeds brain tumours: 400 new cases / year
Full clinical annotation and samples <100% complete

CCLG Tissue Bank

Children's Cancer and Leukaemia Group

40 YEARS SAVING YOUNG LIVES

BRAIN UK

World's first national virtual brain bank

brainstrust the brain cancer people

BNS British Neuropathological Society

MRC Medical Research Council

Brain Tumour Research Funding the fight

BRAIN UK is a collaboration between 26 NHS Neuropathology Centres across the UK, giving effective coverage of 90% of UK population. The British Neuropathological Society, British Neuro-oncology Society, Brain Tumour Network, Medical Research Council and National Cancer Research Institute Brain Tumour Clinical Studies Group have provided input into and support for the project.

Adult primary brain tumours: ~10,500 new cases / year

Adult metastases: ~27,000 new cases / year

No / basic clinical annotation!

3. Resources for biobanking

• Patient

• Surgeon

• Neuropathologist

• Laboratory staff

• Hardware & consumables

- (from routine NHS resources!)

• Top tumour nurses!

• The essential paperwork

NHS
National Institute for Health Research
Clinical Research Network

Certificate of Completion

Michael Jenkinson

has completed

Introduction to Good Clinical Practice (GCP) e-learning course

- Ethics approval / Informed consent
- Anonymised data
- Disclose that discovery may have commercial value
- Disclose academic and commercial partners
- Governance structure / oversight
- Tissue quality assurance

BRAIN TUMOUR NORTH WEST

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CONSENT FORM

Please stick patient hospital label here

WRTB no: _____

Histology no: _____

Title of Project:

Nervous System Tissue and/or Blood Collections for Research (Tumour and non-tumour sample donation)

Walton Research Tissue Bank

Name of Researchers: Mr A Brodbelt, Mr M Jenkinson, Ms C Gilkes, other Walton Centre Consultant Neurosurgeons, Dr D Crooks, Dr B Haylock, Dr D Husband, Dr A Shenoy.

Please Initial box

1. **I confirm** that I have read and **understand the information sheet** dated …….. (Version……) and I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, w ithout my medical care or legal rights being affected. ☐
2. **I understand** that sections of any of my medical records from The Walton Centre, Clatterbridge Cancer Centre or elsewhere may be looked at and information taken from them to be analysed in strict confidence by responsible individuals from the research team or from regulatory authorities where it is relevant to my taking part in research. I give permission for these individuals to have access to my records. ☐
3. **Consent for storage and use in current and future research projects:** I agree that the samples I have given and the information gathered about me can be stored by the Tissue Bank, Neuropathology unit at The Walton Centre for current and future projects, subject to additional project specific ethical approval. ☐
4. **I understand** that some of these projects may be carried out by researchers other than The Walton Centre NHS, including researchers working at National and International level and also working for commercial companies. ☐
5. **I agree** to give samples/data taken, as a gift, for research as detailed in the patient information sheet and I am aware that I am not entitled to any financial gain. ☐
6. **Genetic research:** I understand that my samples may be used in genetic research aimed at understanding the genetic influences on tumours, but that the results of these investigations are unlikely to have any implications for me personally and **I agree to take part in the above study.** ☐

Please Name, Date and Sign

Name of Patient:	**Date:**	**Signature:**
Person taking consent: (if different from researcher):	**Date:**	**Signature:**
Name of Researcher:	**Date:**	**Signature:**

Thank you for agreeing to participate in this research

White copy for Tumour Bank, Blue copy to be kept in hospital notes & Pink copy for consultee/patient

Consent Form for use at the Walton Centre or Clatterbridge Cancer Centre:

Websites: www.thewaltoncentre.nhs.uk/ www.clatterbridgecc.nhs.uk/ www.btnw.org.uk/

Wales REC 4 REC No 15/WA/0385 Version 5 01/10/2015

4. Biobanking in Liverpool

- 1995 – 2010:
  - Project specific ethical approval
  - New ethics for every new project
  - Time consuming
  - Could only target eligible patients for collection
  - Missed opportunity to collect samples from
    - rare brain tumours e.g. pineal
    - AND common tumours e.g. meningioma!

Established 2011 – Dr Carol Walker

The Walton Centre NHS
NHS Foundation Trust

The Clatterbridge Cancer Centre NHS
NHS Foundation Trust

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Websites: www.thewaltoncentre.nhs.uk/ www.clatterbridgecc.nhs.uk/ www.btnw.org.uk/

Patient Information Sheet for tumour and non-tumour sample donation

Nervous System Tissue and/or Blood Collections for Research
Walton Research Tissue Bank

Name of Researchers: Mr A Brodbelt, Mr M Jenkinson, Ms C Gilkes, other Walton Centre Consultant Neurosurgeons, Dr D Crooks, Dr B Haylock, Dr D Husband, Dr A Shenoy

We would like to invite you to take part in our research study. Before you decide we would like you to understand why the research is being done and what it would involve for you. One of our team will go through the information sheet with you and answer any questions you have. We'd suggest this should take about 30 minutes. Talk to others about the study if you wish. Ask us if there is anything that is not clear.

Walton Pathway

The Walton Centre NHS
NHS Foundation Trust

Excellence in Neuroscience

Patient in pre-surgery clinic

Consented for Tissue Bank

All samples sent fresh to pathology laboratory

- Clinical details
- Questionnaires
- Imaging data
- Path Reports

Complete Sample Set

Associated Clinical data

Frozen tissue
Fixed tissue
Cell cultures

Serum
Plasma
Cell fraction

Embed biobanking within the clinical service

WRTB Recruitment (Jan-Dec 2016)

Tumour type	Not clear	GD I	GD II	GD III	GD IV	Total
Astrocytoma	_	2	15	8	_	25
Oligoastrocytoma	_	_	3	1	_	4
Oligodendroglioma	_	_	9	3	_	12
Ependymoma	_	1	1	2	_	4
Gliomas (infiltrating)		_	2	2	_	4
Glioblastoma (GBM)	_	_	_	_	90	90
Gliosarcoma	_	_	_	_	1	1
Total Gliomas						**140**
Meningiomas	1	38	23	0	_	62
Pitutary Adenoma						30
Metastases						48
Schwannoma	_	21	_	_	_	21
Haemangioblastoma	_	4	_	_	_	4
Lymphoma						2
Others						36
Grand total						**343**

WRTB Recruitment (Jan-Dec 2016)

WRTB	2016
Total Patients	343
Total Frozen tissues	220
Total Blood samples	305
Generated	
Serum samples	610
Plasma samples	610
Cell fraction samples	305
EDTA blood samples	0
Samples released	
Tissue samples released	131
Blood samples released	6

WRTB projects supported

WRTB Established	**2011**
Total Projects (2011-2016)	31
Total Ongoing/Active Projects	18
Type of Project (tumour based)	**Number**
High Grade Gliomas	8
Low Grade Gliomas	9
Metastases	5
Meningiomas	4
Others	5
Total	**31**
BRAIN UK Projects	**3**

Brain metastases

Meningioma

Glioma

5. Future of UK biobanking (Swiss versus Greek bank)

- Patients feel biobanks have a duty to make sure the tissue they donate is used for research

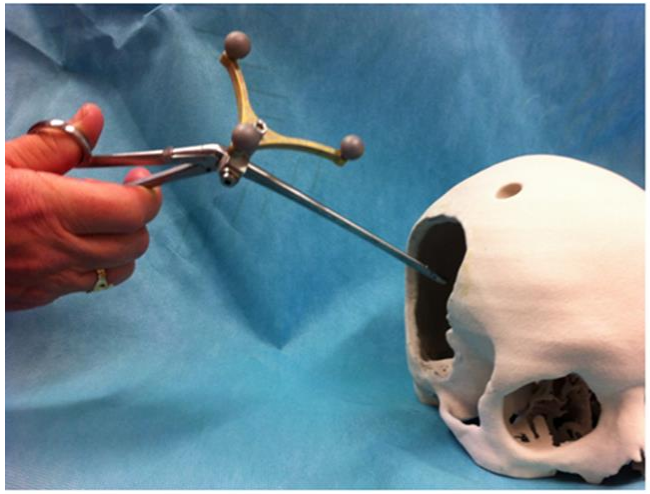
Linking to existing data sets

- Biobanks are resource intensive
- Can we link tissue to existing data sets?
  - E.g. National Cancer Registry
- Can patients contribute to their own data sets?
  - E.g. online repositories
- Can AHPs promote biobanking / contribute to data collection?

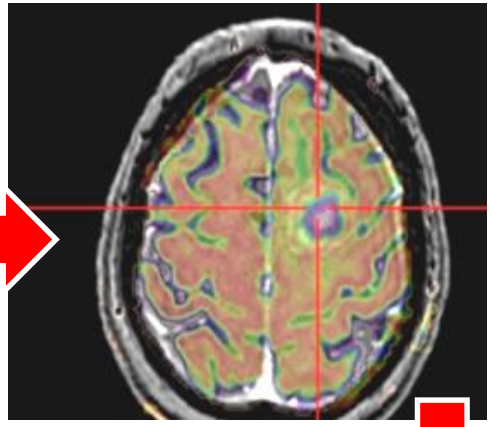
Advanced biobanking initiatives

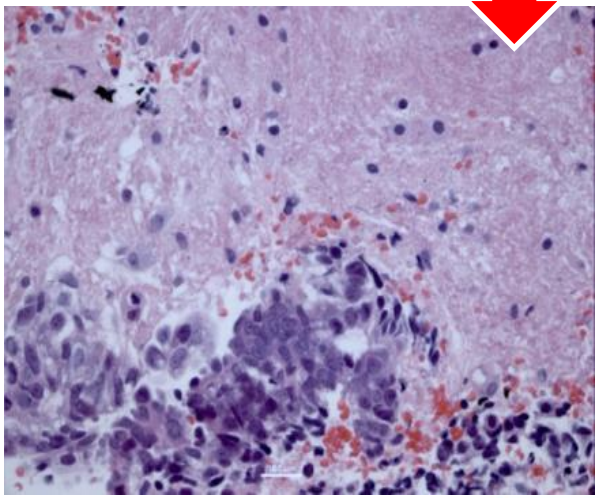
- Multiples samples for intratumoural heterogeneity
- Longitudinal samples for evolutionary biology
  - primary and recurrent glioma
  - low to high grade transformation
- Paired samples from metastases for clonal evolution

Prospective study of leading edge



StealthStation® | S7™





The Neuroradiology Journal 27: 422-424, 2014 - doi: 10.15274/NRJ-2014-10075 www.centauro.it

Using ADC Maps with Structural Scans to Improve Intraoperative Biopsy Specimens in Brain Metastases

RASHEED ZAKARIA[1,2], MICHAEL D. JENKINSON[1]

NRJ THE NEURORADIOLOGY JOURNAL

The Walton Centre NHS
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Scientific meritocracy

- Fully annotated samples are a valuable resource
- Access to high quantity of brain tumour tissue is competitive
- Samples should go to the best research project

Improved networking

- Existing prospective biobanks
- Standardise SOPs
- Set targets for tumour types and samples
- Align collection to scientific questions

6. Conclusions

- Patients value the opportunity to contribute
- Collaborative working (clinic + science=translational)
- Tumour biology / Identifying new targets for therapy
- Future patient benefit

7. Acknowledgements / Collaborations

Tumour CNS

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Anna Visca

Trainees

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David GIraldi

Neuropathology lab

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Nitika Rathi
Neil Moxham
Carrie Chadwick
Wallis Simpson-Hayes
Amanda Davies

Neuroradiology

Kumar Das
Maneesh Bhojak
Samantha Mills