

Existing UK tissue banked from adolescent / young adult cancer patients

Martin McCabe, University of Manchester
on behalf of NCRI Teenage / Young Adult Clinical Studies Group

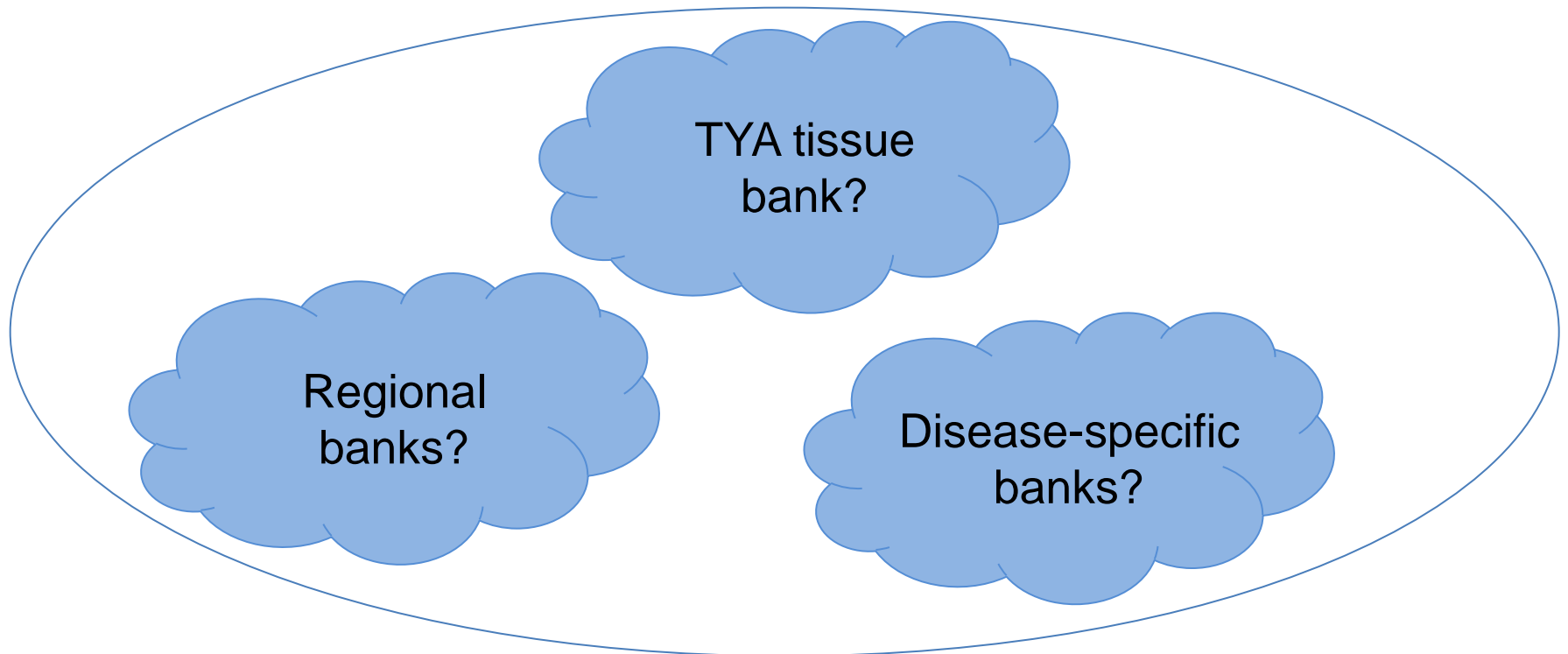
TYA CSG Biological Studies Group

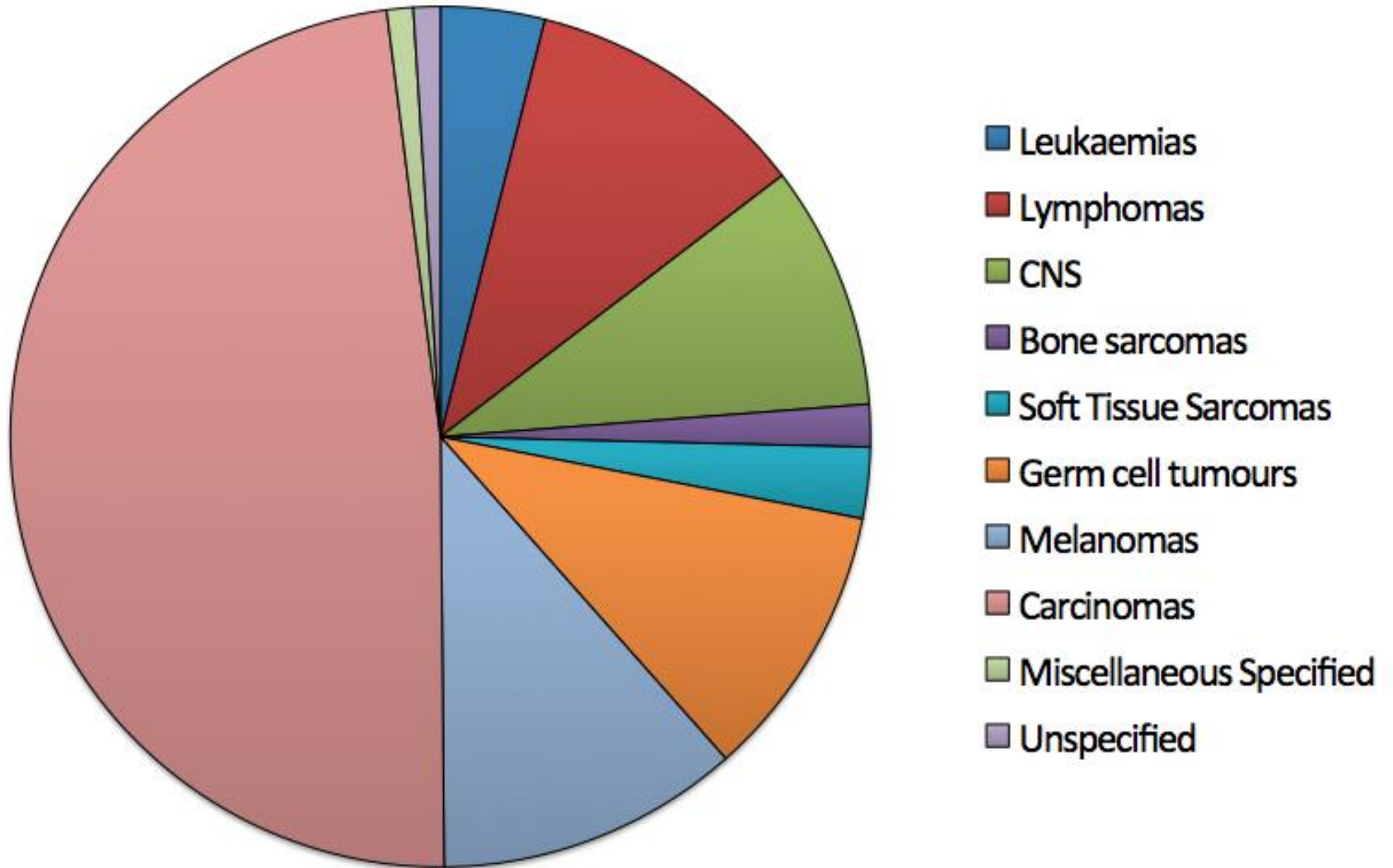
Cross-cutting biological studies relevant to teenage and young adult cancer

- Personalised medicine
- Age-related pharmacokinetics
- Genetic predisposition
- Disease-specific biology
- Tissue banking

TYA tissue banking

Imperative to 'sort it out' from NCRI







The University of Manchester



Children's
Cancer and
Leukaemia
Group

**Tissue
Bank**

In association with



Newcastle
University



UNIVERSITY OF
LEICESTER

Scoping exercise - NCRI Confederation of Cancer Biobanks

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Quality standard (v1.0 March 2014)

‘The biobank shall have documented access policies and procedures, which are communicated to potential applicants.’

Scoping exercise - NCRI Confederation of Cancer Biobanks

Quality standard (v1.0 March 2014)

‘The access policy shall be stated clearly and referenced in all of the biobank's donor-facing and client-facing media. The policy shall ensure that *bona fide* researchers in any sector can be granted access to samples and data.’

Scoping exercise - NCRI Confederation of Cancer Biobanks

Quality standard (v1.0 March 2014)

‘The biobank shall ensure that operational policies do not preclude involvement by any individual or group, or justify clearly why exclusive policies exist.’

Scoping exercise - NCRI Confederation of Cancer Biobanks

Do you have samples on patients aged 13-39 years?

Age	Number of donors
13-14	
15-19	
20-24	
25-29	
30-34	
35-39	

Histological breakdown

Initial diagnosis / relapse

Associated metadata:

- age
- address
- gender
- staging data
- clinical symptoms
- treatment
- trial recruitment
- outcomes

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Initial contact March 2012 (n=24)



Reminder July 2012



Personal approach to non-responders → replies from 13/24



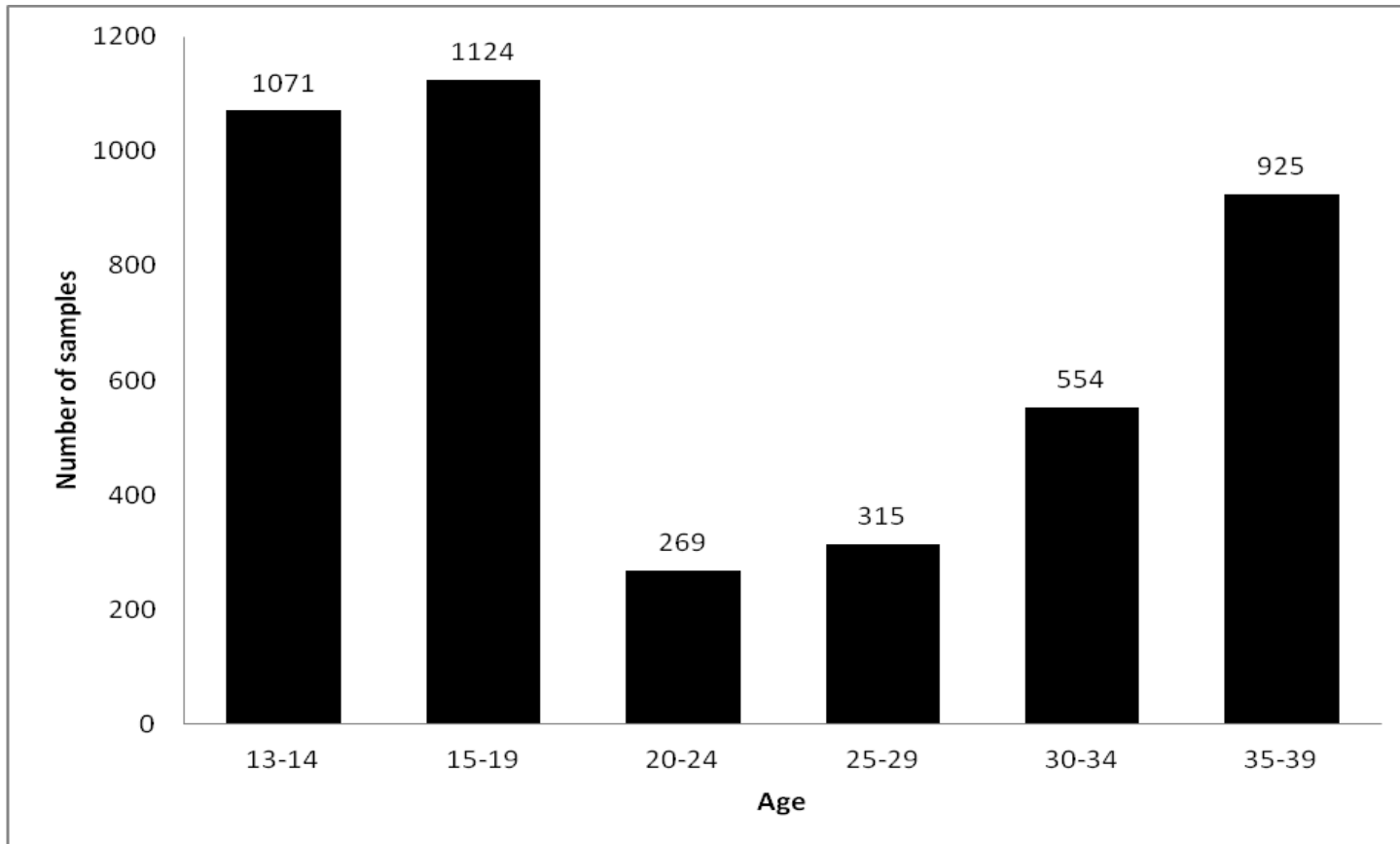
Exercise repeated March 2014 (n=38)
(updated data for previous responders)

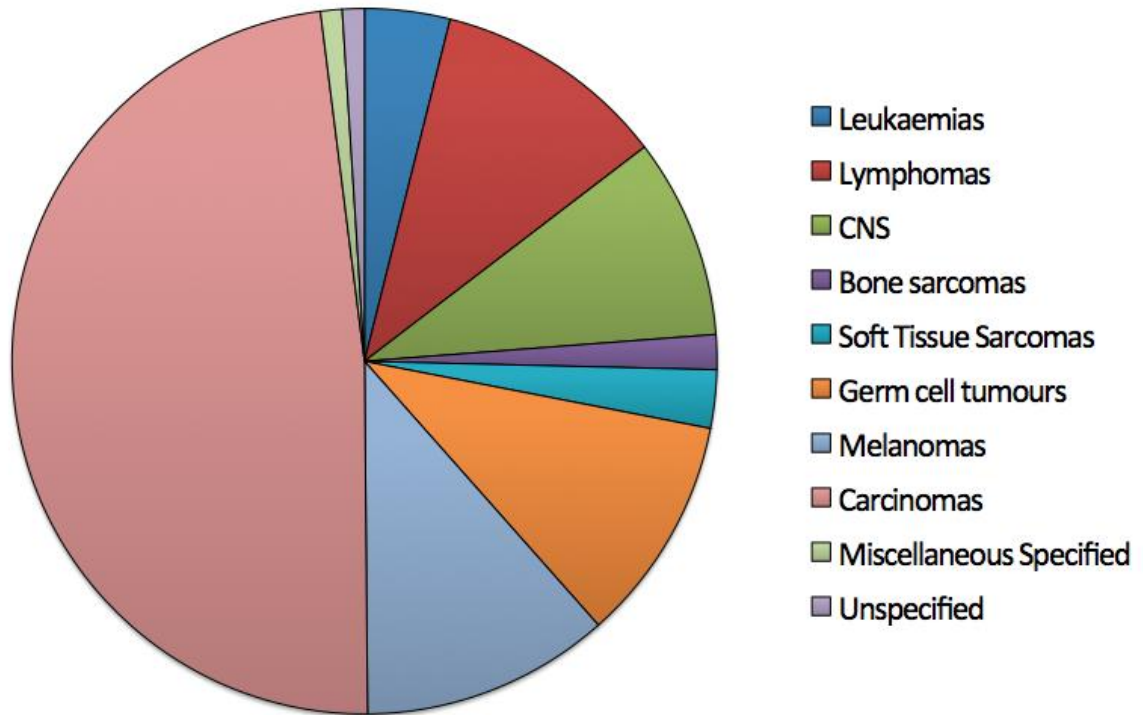
Scoping exercise - NCRI Confederation of Cancer Biobanks

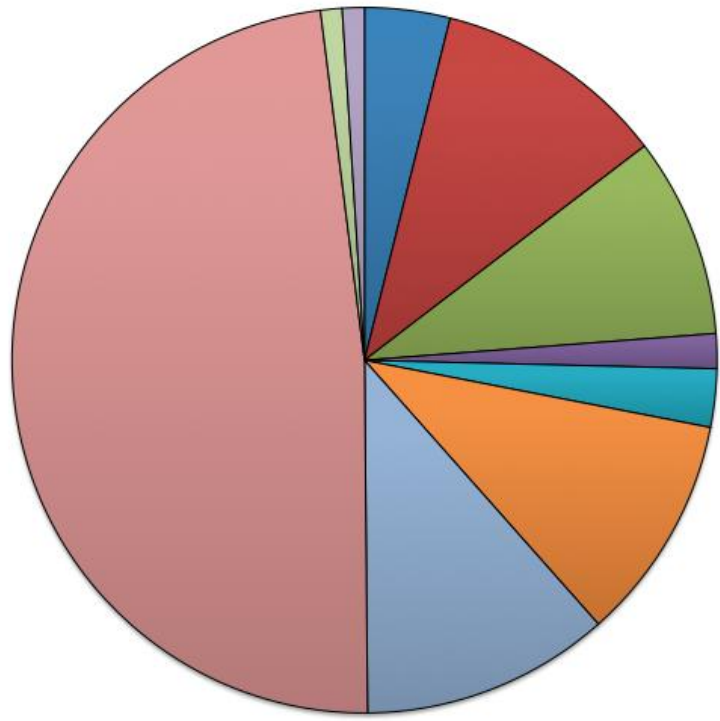
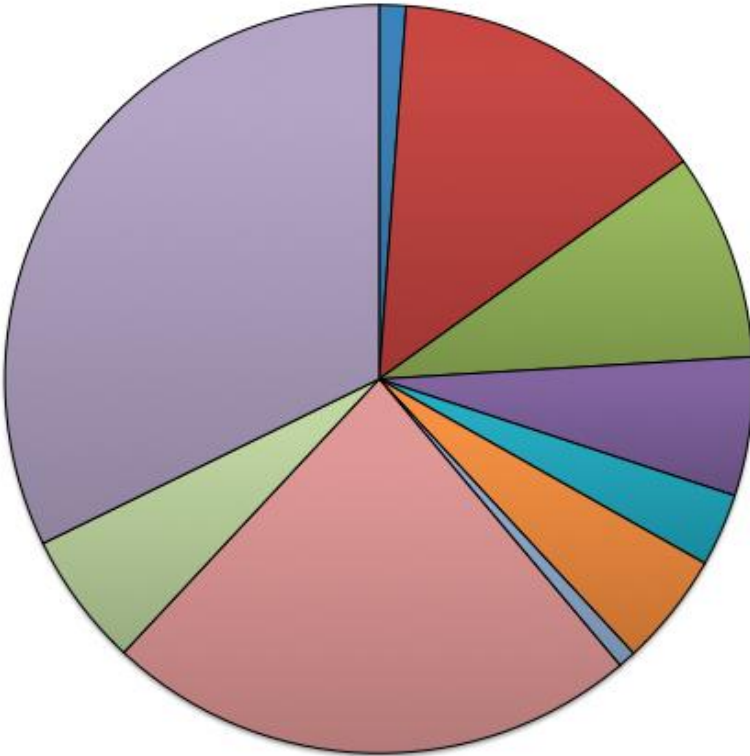
Replies from **15/38 CCB biobanks** despite at least 2 attempts for each

Evidence of **3651 'malignant'** and **404 benign** tumours
(cf ~2500 new diagnoses per year in UK)

Scoping exercise - NCRI Confederation of Cancer Biobanks







- Leukaemias
- Lymphomas
- CNS
- Bone sarcomas
- Soft Tissue Sarcomas
- Germ cell tumours
- Melanomas
- Carcinomas
- Miscellaneous Specified
- Unspecified

Conclusions

Very few samples banked

Difficult to access information about what is available

Significant proportion of CCB biobanks are not adhering to quality standard regarding data access

Banked samples are not representative of incident cases

Case for a specific TYA tissue banking initiative