Work of the Lead Registry
for Bone and Soft Tissue Sarcoma

NCIN Clinical Leads Workshop
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Overview

- What is the NCIN?

- What data do we have?

- Initial analysis

- Future work plan

- How you can help

The
National Cancer Intelligence Network

Using information to improve quality and choice

- Launched June 2008
- Data collection, national data, analysis, supporting audit and research
- Cancer registries, health service researches, clinical champions…
- Under auspices of National Cancer Research Institute

Lead Cancer Registries

Map of England and Wales showing lead cancer registries:
- **Northern & Yorkshire** — *Colorectal and Haematological*
- **North West** — *Children & Teenage Young Adults*
- **Trent** — *Gynaecological*
- **Wales**
- **West Midlands** — *Breast and Sarcoma*
- **Eastern** — *Brain & Central Nervous System*
- **Oxford** — *Head & Neck*
- **Thames** — *Lung (inc Mesothelioma) and Upper GI (inc HPB)*
- **South West** — *Skin and Urological*

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- Each Registry takes a lead on one (or more) cancer sites

- Initially 11 cancer sites chosen

- West Midlands is the lead for
  - Breast
  - Sarcoma

West Midlands Cancer Intelligence Unit

West Midlands Cancer Intelligence Unit

Lead registry for Bone and Soft Tissue Sarcoma

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Director

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What data do we have?

- Cancer Registry data

- Hospital Episode Statistics

- Other data sources

Cancer Registry Data

- Data from all 8 of the English cancer registries

- Historical data goes back in time until 1979

- Population based

- Data items cover key information about:
  - The patient: age, sex, postcode, date of death
  - The tumour: site, morphology, stage…
  - Some treatment data

Cancer Registry Data

- Path labs and death certificates have historically been the main source of data,
    although many registries now collect a wide range of sources.

- Cancer registries all strive to collect at least the minimum cancer data set
    … and strive to code in a consistent and standardised way

- However, data completeness, coding and quality may vary slightly between registries and over time – NCIN and UKACR working together to understand and resolve any issues.

ukacr
United Kingdom
Association of
Cancer Registries

Hospital Episode Statistics

- Data from all NHS hospitals in England

- Cover the financial years 1997/98 – 2005/06

- Data items cover key information about:
  - The patient: age, sex, postcode, date of death
  - Their admissions into hospital
    When, where, diagnosis, operation, treating surgeon

- Data don't cover tumour pathology, or date of death.

- Only NHS patients – private patients or patients not seen in hospital excluded.

Data Linkage

Cancer Registry Data   **Hospital Episode Statistics**

First time we have had national linked data

Linking the data sets together increases the power of both!

Other Data Sources

The WMCIU

**or at least
YOUR DATA!**

- With more data sources we can
  - link data sources together
  - Analyse more variables
  - Do data quality checks on data we already have

- Do you know of a database we could be using?
- Do you have a database you can share with us?

What analysis have we done?

- Initial Analysis – mostly bone

- Location of treatment

- Spinal and Sacral Tumours
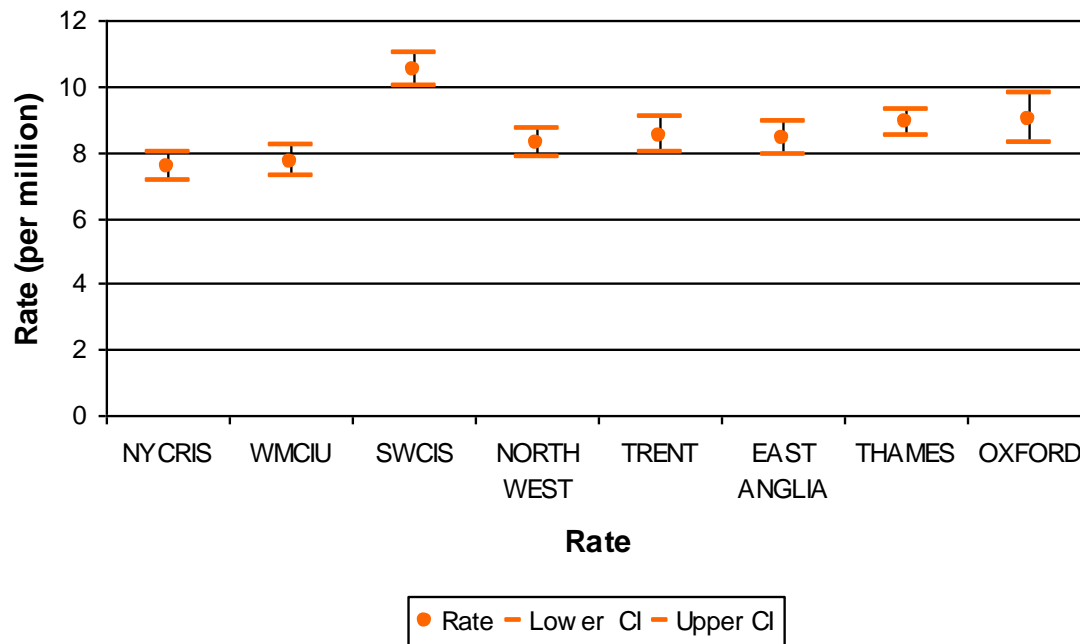
Trends over time
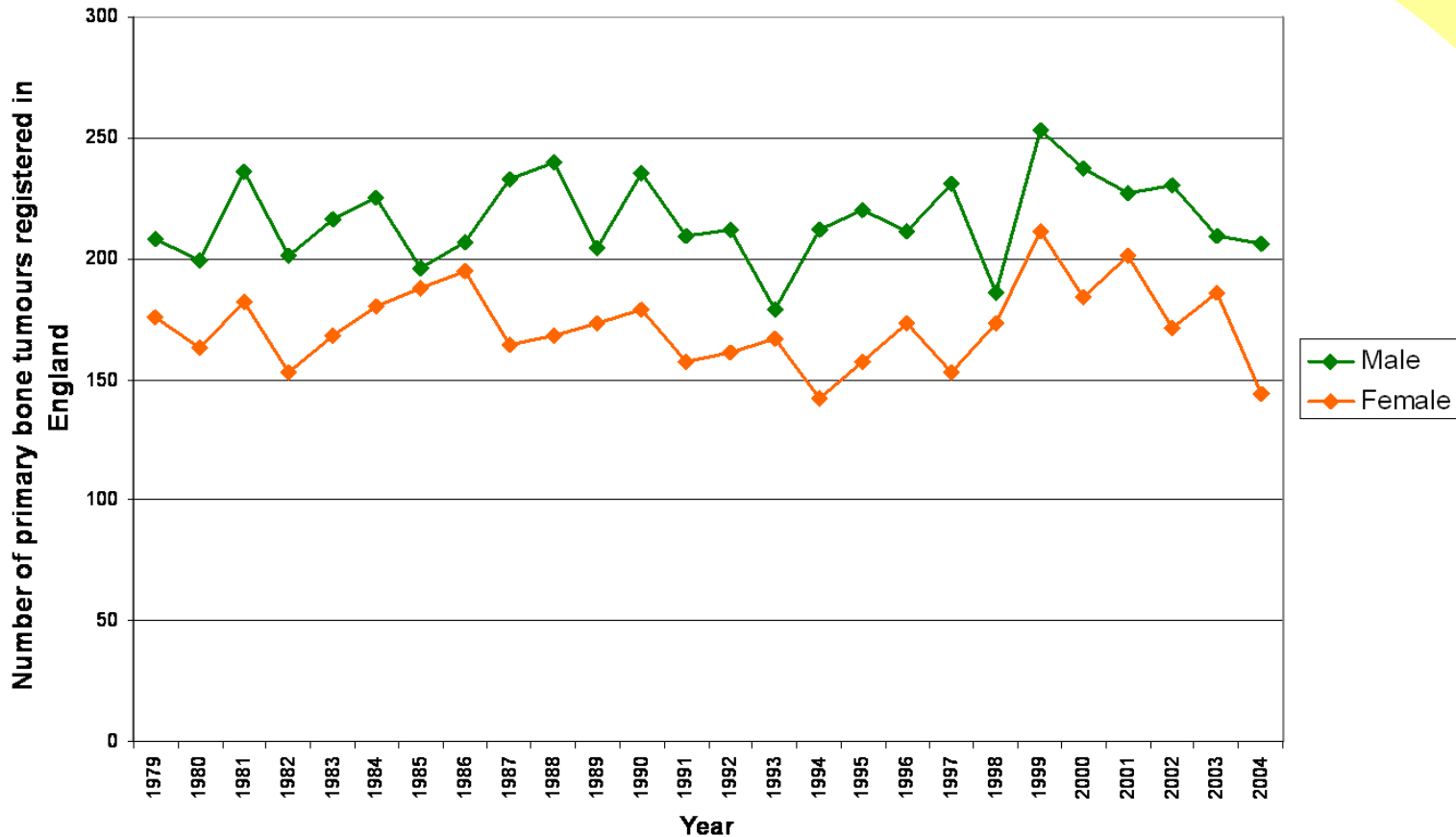
Incidence data from 1979 – 2004 analysed for trends

Beware coding changes as well as genuine trends!
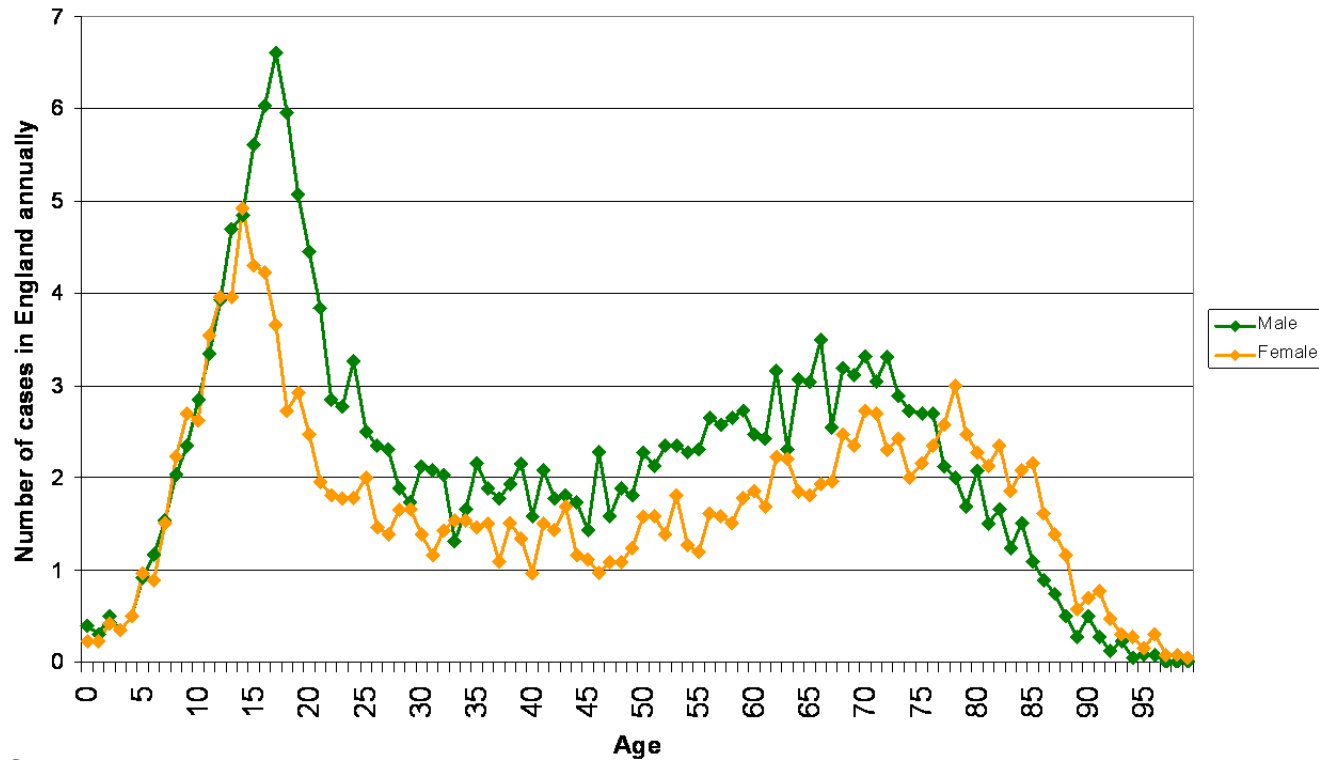
Geographical variation

Bone Sarcoma Rates - 1979 - 2004 by Registry

Analyse data from across England by region

Looking for possible coding variation as well as variation in incidence!

Age profiles

Bone Sarcoma 1979 - 2004

National data allows detailed age profiles to be seen

Trust Caseload - Bone

- For HES data from 1997/98 to 2004/05, 100 Trusts were identified performing a total of 1,218 surgical operations on patients with bone sarcoma

- On average 12 operations per Trust – but the profile is very different

- The highest caseload centre oversaw 396 operations - 33%

- Two very high caseload specialised Trusts
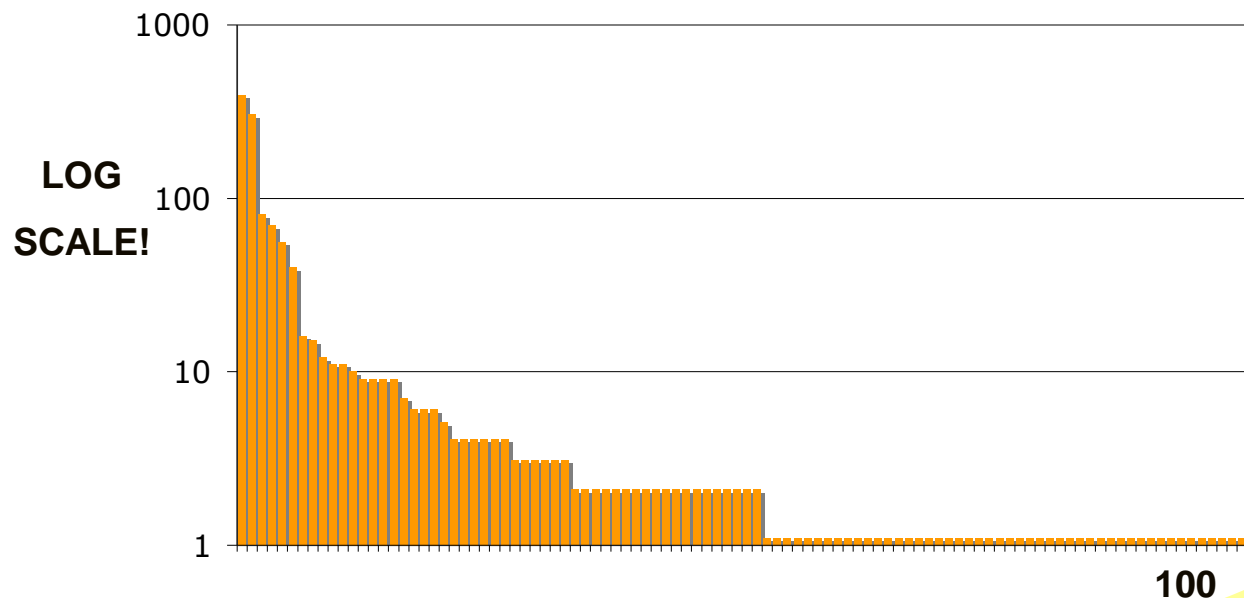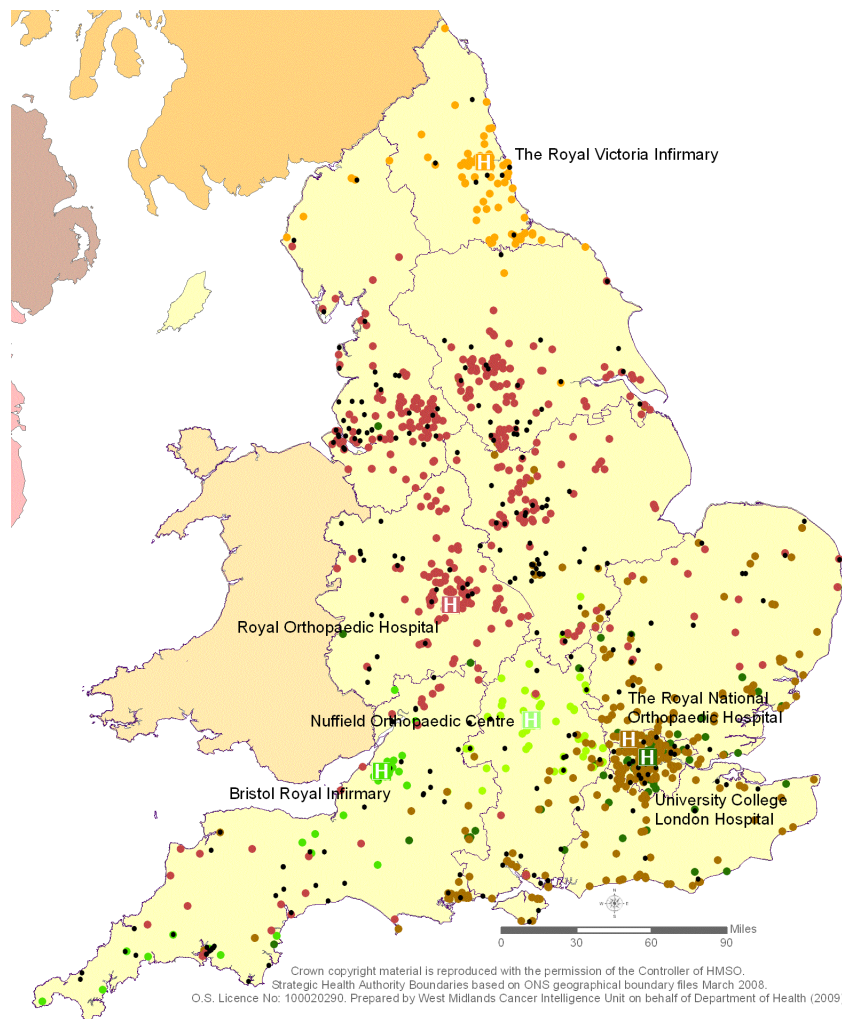
LOG SCALE!
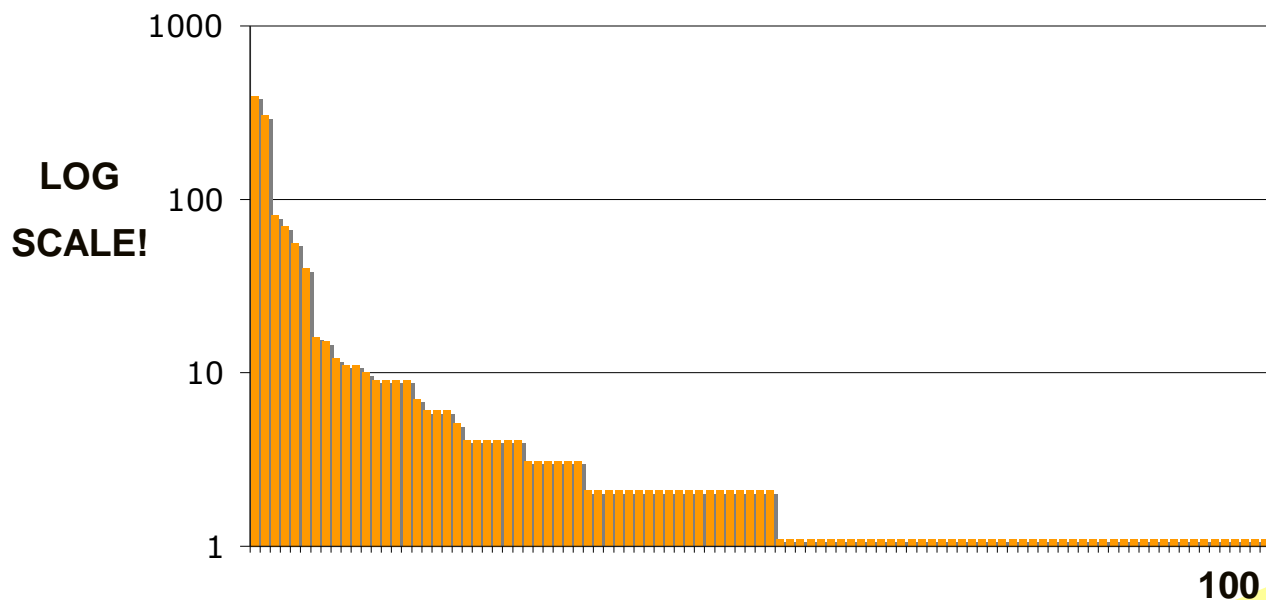
Trust Caseload - Bone

- First analysis of data leads to key questions

  - Are these data correct?

  - What operations were done in the low caseload Trusts? Were they emergency admissions?

  - Is it best to look at most recent data only, even though numbers are small? Is our HES data too old? – a new HES refresh is coming soon!

Referral patterns (Bone)

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- Two specialist centres treated the majority of patients from across England

- Patients in geographically isolated parts of England (the North, the South West) are more likely to be treated in a lower caseload centre

- In central England patients have a diverse three way referral pattern

- Referral patterns are changing over time – the operations in less specialised Trusts reduce

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Spinal and Sacral Tumours

- Wanted estimate of base of skull, spinal and sacral tumours

    - Understand possible population who could benefit from proton therapy

- However, no codes for 'sacral', just for 'sacrum, coccyx and pelvis'

- No codes for 'base of skull', just 'skull'

Identifying Sacral Tumours

- WMCIU has full pathology reports etc for West Midlands tumours
- Surveyed 49 tumours coded to 'sacrum, coccyx or pelvis'
- Found subsite by morphology

Morphology	Sub-site			Grand Total	% relevant site
	Other	Pelvis	Sacrum		
Central osteosarcoma		1		1	0%
Chondroblastic osteosarcoma			1	1	100%
Chondrosarcoma	2	8	3	13	23%
Chordoma			6	6	100%
Ewing sarcoma		13	1	14	7%
Fibroblastic osteosarcoma		1		1	0%
Osteosarcoma	2	10		12	0%
Osteosarcoma in Paget disease			1	1	100%
Grand Total	4	33	12	49	25%

Spinal and Sacral Tumours

- Applied the estimates to national data

- Did similar survey for base of skull tumours

- Conclude:
  - Approx 30 spinal and sacral tumours annually in England
  - Approx 4 base of skull tumours annually in England

- National data provide the best way of estimating the incidence of very rare tumours

Spinal and Sacral Tumours

- Analysis based on very small numbers of tumours as rare condition

- Are our site codes fit for purpose?

- Do we need to collect more detailed sub sites so we don't need to estimate?

- These ideas feed into the national dataset project...

Future work:
Core epidemiology

- Define morphologies and sites for main sarcoma groupings

- Produce key epidemiological stats for these
  - Incidence, mortality, survival, prevalence

- Profile populations to understand effect of age, socio-economic status, sex, etc on risk

- Long term outcomes – length of remission, recurrences

- Any correlations with other primary tumours

Future work:
Data Quality

- Analysis of completeness of data

- Development of sarcoma dataset as part of National Cancer Dataset

- Pilot of central data collection

- Improved data quality process – direct feedback to surgeons

- Linkage of more datasets eg Going Forward on Cancer Waits

Future work:
Service Monitoring and Planning

- Length of patient pathway – time to reach specialist

- Surgeon caseload and specialisation

- Measures of IoG implementation

- Provide analysis to support NICE technology appraisals

- Treatment pathways for specific rare tumours

- Identification of key information needs

Future work:
Communications

- Website

- NCIN publications

- Factsheets

- Nomograms

How can you help?

- Make suggestions for what should be on our work programme, and what we should prioritise

- Work with us on research projects

- Share data sets with us
  - do you have a database that collects more than basic HES data?

- Engage with data quality projects
  - check that the data we have on your patients looks correct to you!

- Sign up to read our reports and factsheets
  - and feed back to us about what is helpful!