# Visualising words Uncovering hidden information in large UK primary care databases

Rosemary Tate on behalf of the" Patient Records Enhancement Project", Brighton and Sussex Medical School and Department of Informatics at University of Sussex,

#### Structure of talk

- The role of General Practice in the UK
- The General Practice Research Database
- Why GPRD researchers need visualisation tools
- Example ovarian cancer study
- Open questions

#### The UK National Health Service: Role of General Practitioner



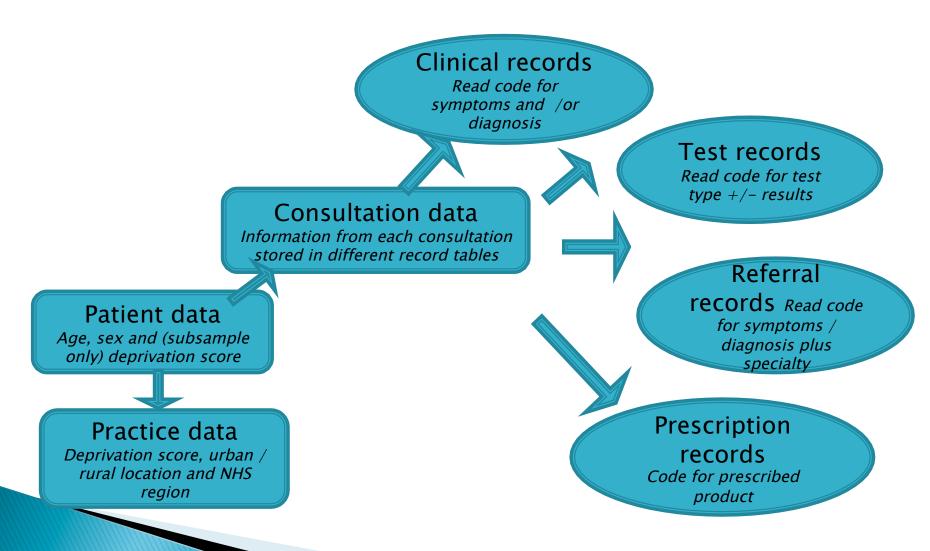
## General practitioner (GP) systems in the UK

- Have been recording electronically since the early 1980s
- Systems provide a huge amount of flexibility for recording
- Many different (Read) codes for the same thing
- May also use free text

## General Practice Research Database (GPRD) http://www.gprd.com

- Collections from 620 practices (~7% of UK practices)
- Contains over 12.5 million patients
- ▶ 5 million active (alive) patients (~8% popn.)
- Contains over 62 million patient-years of follow up
- Geographically representative of UK

#### Structure of GPRD database



## Why GPRD researchers need visualisation tools

- Track for early indicators of diagnoses
- Check data quality
- Develop models of patients' journey through cancer
- Define definitions of 'cases'
- Annotate and edit the data; e.g., add causal links

## Example: Ovarian cancer study

- Investigating symptoms and delay in diagnosis
- 344 patients with ovarian cancer
- Using data from the General Practice research database

## Ovarian cancer study

Compared incidence of 5 most common symptoms in the year prior to diagnosis using

- ▶ 1. codes
- 2. free text (notes and letters) mapped symptoms in text to "pseudo" Read codes

Results: Incidence doubled for some symptoms when we used the free text

Challenge - how to extract and present this extra information?

#### Typical patient record shown on a timeline



#### **Abdominal pain**

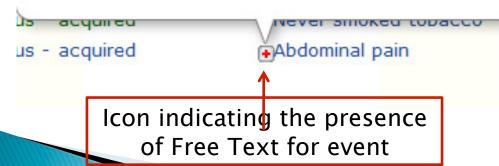
Patient ID: 6432912

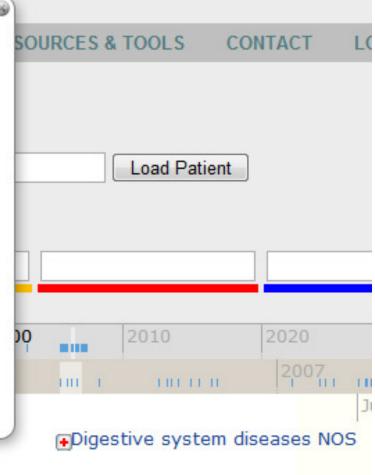
**Description:** Abdominal pain

Category: From Clinical

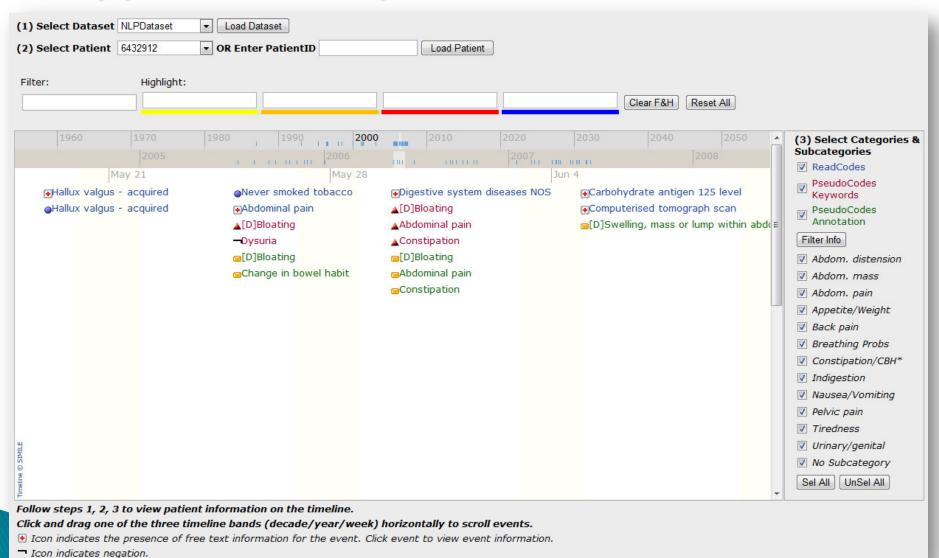
Free Text: ~ bloating in 90's && relapsed last 1/52 - worse after meals , no wind. BO daily - now alternating , no rectal bleeding , gen health app + wt ok. No dyspesia , no dysuria , only 2 K this year. FH - no Ca bowel / Ovary o / we abdo - soft no tender no LKKS. Imp IBS - tca if persists

Thu, 25 May 2006 00:00:00 GMT

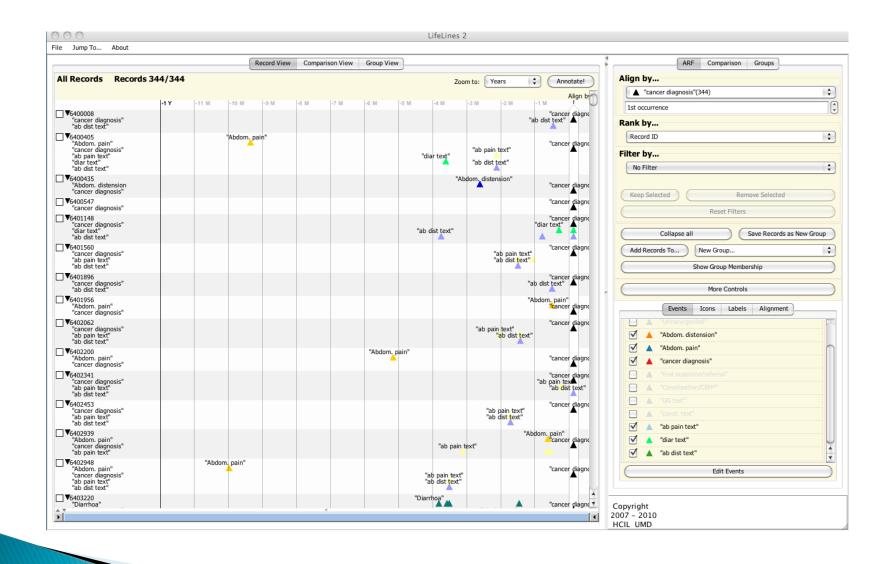




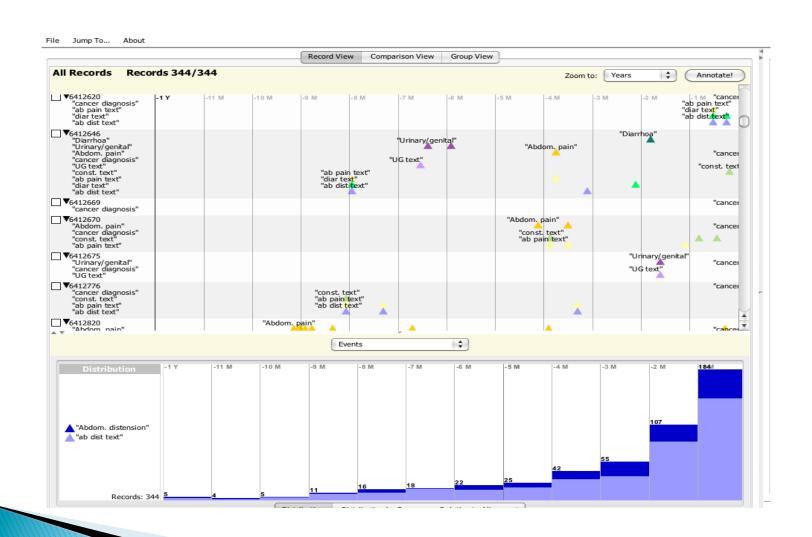
#### Mapped text to "pseudo" Read codes



#### LifeLines2 to show differences between free text and coded information



#### LifeLines2 to show differences between free text and coded information



### Open questions

- How to present information at different levels of detail – show both the big picture and the individual records
- How to present information hidden in the free text?
- Provide for user interaction
- Accommodate for a range of user tasks

### Acknowledgements

Aishath Ali<sup>1</sup>
John Carroll<sup>2</sup>
Fliss Henwood<sup>3</sup>
Donia Scott<sup>2</sup>

Lesley Axelrod<sup>2</sup>
Jackie Cassell<sup>1</sup>
Rob Koeling<sup>2</sup>
Tim Williams<sup>4</sup>

- ¹Division of Primary care, Brighton and Sussex Medical School
- Dept of Informatics, University of Sussex
- 3 Applied Social Sciences, University of Brighton
- <sup>4</sup> General Practice Research Database, MHRA, London

The Team

