

Using timelines to depict patient journeys: a development for research methods and clinical care review

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Graphical displays of investigations are increasingly used in clinical care. Summaries of medical records for research or clinical review purposes can generate unmanageably large amounts of data, which may be helpfully summarised and displayed using timelines. During a prospective study of cancer care in primary care, care timelines were generated in Microsoft Visio, using data collected retrospectively from general practice records. Data from primary and secondary care consultations were included. Thirteen timelines were created, which proved valuable in summarising and analysing the data concerning the cases studied. Timelines provide a clear, concise way of displaying large amounts of diverse data, although some selectivity is required to facilitate interpretation. Generation of timelines in the software was time consuming: if they could be automatically generated within clinical IT systems, they would enable clinicians to generate useful summaries of care of complex cases, facilitating care reviews.

Key words: health-care research; methods; primary health care

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Background

Health services and health-care research increasingly utilises case note reviews to investigate patient care. General Practice records are a rich source of diverse types of data from different origins, and are widely used in health-care research; for example, to identify symptoms that patients present with (Wilne *et al.*, 2006; Hayashi *et al.*, 2010) or patterns of care (Daly *et al.*, 2010; Mactier *et al.*, 2011). Such studies can generate large amounts of data, both quantitative and qualitative, especially where patients' journeys are followed for long periods or multiple health-care record

sources are used: it is challenging for researchers to make optimal use of all the data.

Well-designed medical record systems aid understanding of patient information (Wyatt and Wright, 1998). Presentation of patients' test results to show patterns, rather than a list of numbers, or improving formatting has been shown to speed up interpretation (Nygren *et al.*, 1998). A limited amount of information may be initially provided in visual form, enabling health-care professionals to identify where they need to look for more detailed information (Nygren *et al.*, 1998). Health-care professionals value such a 'succinct and streamlined view of the electronic patient record' (Gill *et al.*, 2010) that provide a 'clear, accessible view' of time periods up to 12 months (Plaisant *et al.*, 1998).

We recently undertook a two-phase, mixed method, action research study that aimed to

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introduce and evaluate a template for use by primary care teams with all patients with a new cancer diagnosis. The template, or 'CORD' (Cancer Ongoing Record Document) was designed to encourage delivery and documentation of pro-active cancer care in primary care. Data were collected through case note reviews and interviews with both patients and health-care professionals. This paper aims to describe the use of timelines in the study, which were used to display the data. The findings from the study will be published separately.

Methods

General Practice case note reviews were carried out for 107 consenting patients across 13 practices in England and Scotland, who had received a new diagnosis of cancer within the past 12 months. Both qualitative and quantitative information was collected for each consultation using a data extraction tool designed for the study. Demographic and diagnostic data were collected, with information from all primary and secondary care consultations following the cancer diagnosis: their dates, number, content and clinician involved, with the frequency of CORD use and content of information recorded on the CORD. This created a detailed and complex data set that was entered into SPSS for descriptive statistical analysis.

Timelines were constructed in Microsoft Visio for the 13 patients who were also interviewed. Two parallel lines were created, representing primary care and secondary care. All primary care appointments were entered at their corresponding dates, with the type of appointment (general practitioner or practice nurse; surgery, telephone or home consultation) indicated by a symbol. Key primary care consultations were annotated with reason for attendance, content of discussions and actions taken. Consultations where CORD entries were made were noted, although further details of the CORD entries were not included. The study's focus was on appointments with primary care, but key secondary care appointments, admissions and treatments were added with a brief description to provide context.

Symbols and colours were used to indicate different types of appointment, such as GP or practice nurse, appointment location and treatment courses. A summary box detailing number

of appointments was added, and a clinician member of the research team checked to ensure that all relevant information had been included and data superfluous to the study aims removed.

The timelines were used within the research study in a number of ways: to aid identification of patients for whom further analysis may be of interest; to supplement patient interview data during data analysis; and to illustrate cases during oral presentations of the study.

Examples

Three illustrative timelines are shown below with a key (Figure 1) to allow interpretation of the symbols used.

Figure 2 shows the case study of a patient with metastatic lung cancer, who was followed up for 12 months. Soon after presenting with chest pains, a diagnosis of lung cancer was made from a chest X-ray, following which a high level of contact with primary and secondary care is seen. Primary care consultations were mainly at the patient's home by the GP, covering the side effects of palliative chemotherapy and discussions about future treatment plans and preferred place of death. The CORD was used three times. Despite a preference to die at home, his disease progressed and he was admitted to a hospital after discussion between the patient, his daughter and his GP: he died in the hospital a few days later.

Figure 3 shows the case study of a patient with breast cancer and bone metastases, who was followed up for six months: there were fewer consultations. After presenting with a lump in the breast, and then a change in bowel habit, breast cancer and diverticulitis were diagnosed. Within a

Key

▼	GP – surgery appointment	◆	Secondary care appointment
▲		■	Hospital admission
◆	Nurse – surgery appointment	⊖	Chemotherapy course
▼	GP – telephone appointment	×	Radiotherapy course
●	GP – home appointment		
■	Out of Hours entry		

Figure 1 Key for timelines.

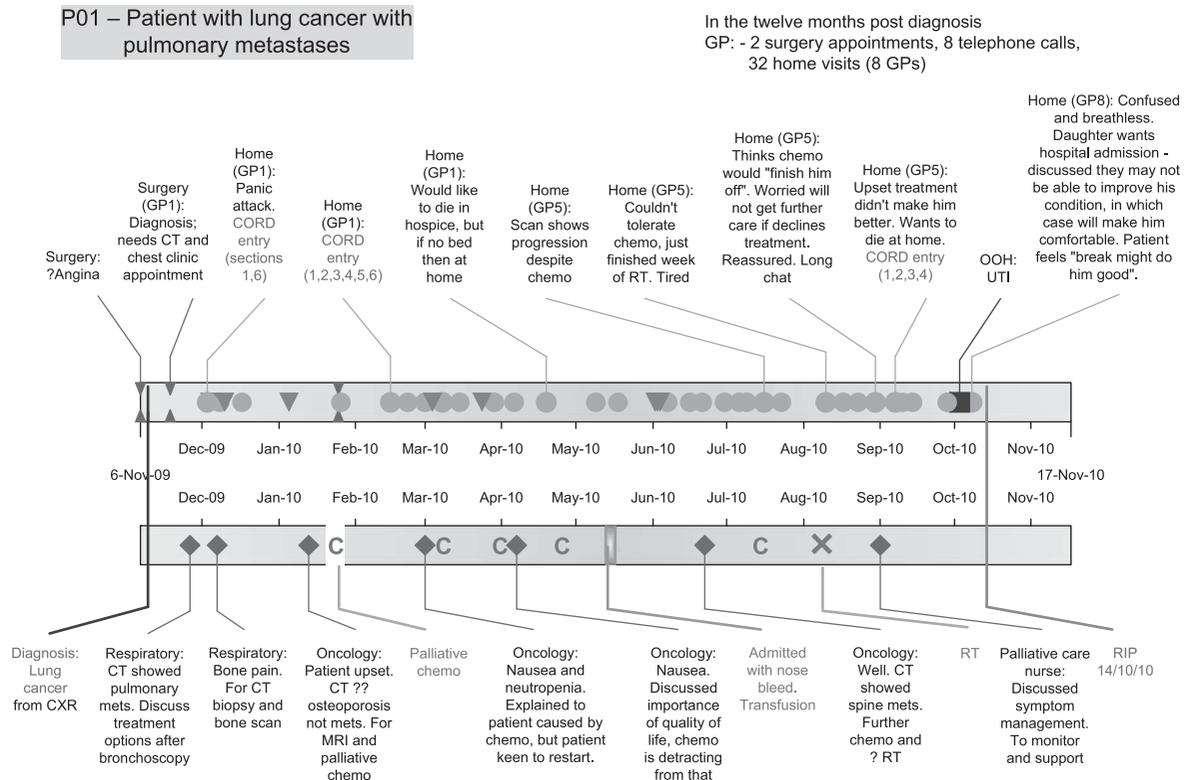


Figure 2 Patient with lung cancer with pulmonary metastases. CORD = Cancer Ongoing Record Document; CT = Computed Tomography; RT = Radiotherapy; OOH = Out of Hours; UTI = Urinary Tract Infection; CXR = Chest X-Ray.

month of the cancer diagnosis, bone metastases were found. Some of the primary care consultations focused on symptoms and co-morbidities, which included renal and respiratory disorders. The patient was unaware of the 'palliative' intent to begin with, despite letters from secondary care professionals suggesting that this had been discussed. Consultations also covered bone pain caused by metastases and the future care of the patient's husband (who had dementia) as the cancer progressed.

Figure 4 shows the case study of a patient with prostate cancer, who was followed up for 12 months after diagnosis, again with relatively few consultations. Following diagnosis, half the primary care consultations were with a practice nurse, mainly for blood sampling and vaccinations. The other half were with GPs, with cancer-related symptoms such as urinary problems being discussed at most consultations.

Discussion

The timelines provide a visualisation of patients' journeys, incorporating a diverse data set from a range of sources. In this study, they were used to aid data analysis and interpretation by the research team during discussions about findings from the study's interviews, which had also produced copious amounts of data. Information from the clinical records had originally been collected in tabular form; transformation of the data to this graphic form was more conducive to discussion, avoiding the need to read two sets of text. They showed how busy the months post-diagnosis often are for patients, families and their primary health-care professionals: they provided another window into our understanding of the interactions between patients and their key health-care professionals at this crucial time. In some cases, it helped highlight discrepancies between the patients' accounts and

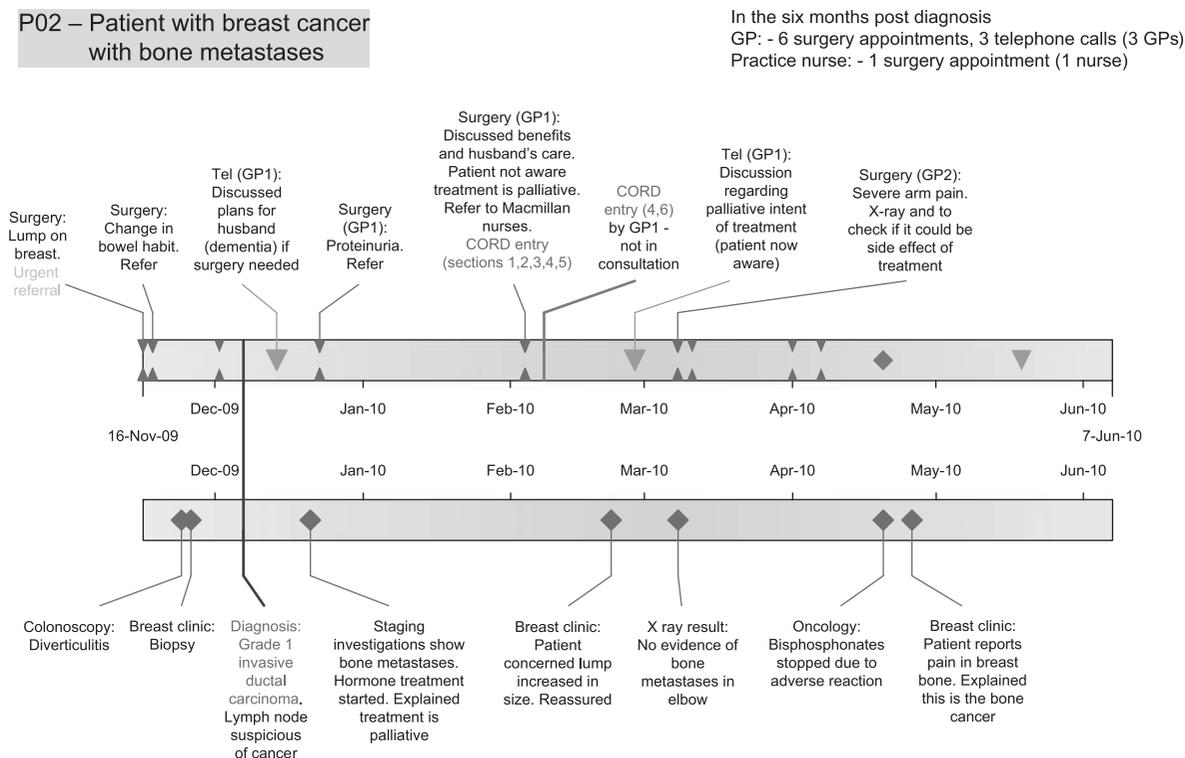


Figure 3 Patient with breast cancer with bone metastases. CORD =Cancer Ongoing Record Document.

the records; for example, if a patient reported little contact with primary care after their diagnosis, but their records suggested they had fairly frequent contact, it was easier to identify the disagreement visually on the timelines than by looking at dates in a table.

Construction of the timelines is time consuming, so they were only used for a subset of patients. The most variable element with regard to time was extraction of the data from the medical records, which varied greatly depending on the amount of contact patients had with health-care professionals; this would have been carried out regardless of the method of data display, because of the type of information needed for this study. Once data were extracted and a template for the timelines created, generation of each timeline took <30 min. In both research and clinical practice it would be helpful for them to be generated automatically from within the electronic medical records system. A 1998 study investigated the feasibility of creating more visual

displays from medical records for clinical use in oncology (Bui *et al.*, 1998), but concluded that commercially available IT systems could not support this. Current clinical information systems are able to generate graphical displays of laboratory values and blood pressure, and could potentially be adapted to also generate care timelines as in this study. Even then, they may still need some 'human input' to identify the information most relevant to the research or clinical context. Information from secondary care letters scanned into the GP system could not be included in all practices if timelines were generated automatically. Gill *et al.* suggested that this would be the case until electronic communication between primary and secondary care becomes routine (Gill *et al.*, 2010); however, in some practices secondary care data were summarised in GP records by members of the administrative team. In these practices, the secondary care data could be included if timelines could be generated within the information systems.

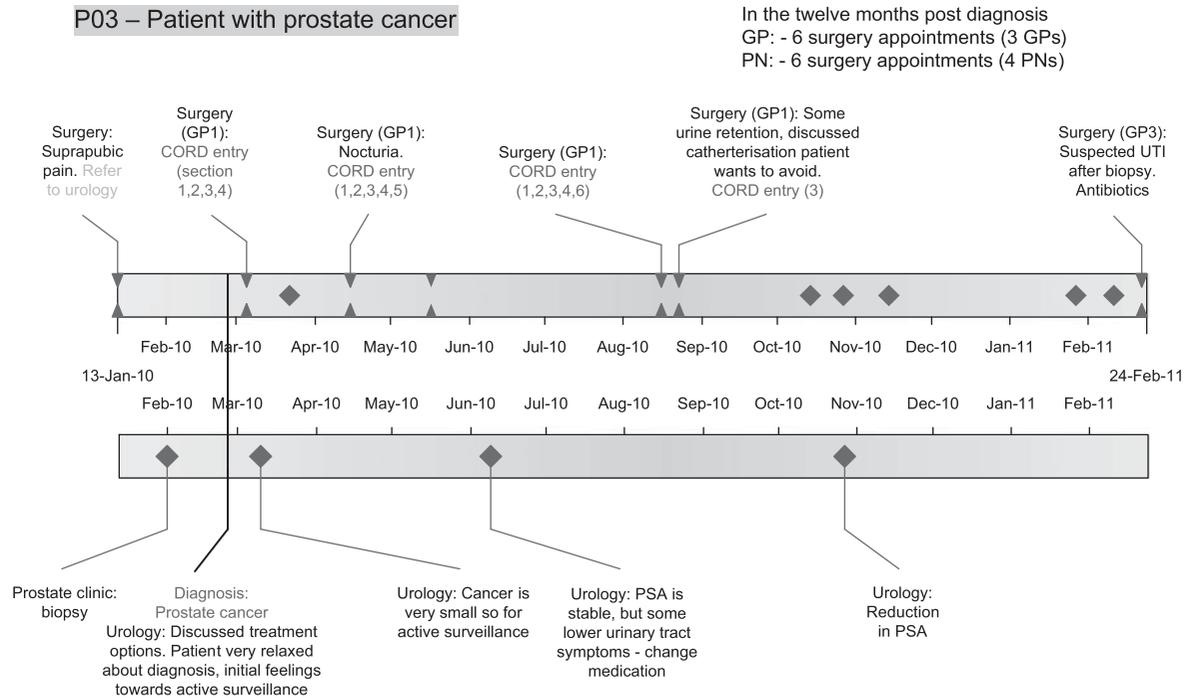


Figure 4 Patient with prostate cancer. CORD = Cancer Ongoing Record Document; UTI = Urinary Tract Infection; PSA = Prostate-Specific Antigen.

Studies have highlighted the effectiveness of graphics in research. Process mapping of patient journeys have been shown to aid health systems research examining clinical efficacy and efficiency (Trebble *et al.*, 2010); mapping of illness trajectories has improved the understanding of progressive deterioration seen in many life-threatening illnesses (Murray *et al.*, 2005). We suggest that clinical care timelines are of particular value in multi-dimensional research or research with patients with multimorbidities. Simultaneous display of information of different aspects of care is possible, showing temporal relationships and the interplay between providers (Bui *et al.*, 1998). The timelines shown in this paper display information relevant to the study that was being worked on. Data would not need to be limited to that regarding content of health-care consultations; information sourced from social care records or clinical test results, for example, could also be included if relevant. In addition, timelines required by other studies may not require information from different care settings like secondary care or differentiation between primary

care consultation types. Timelines can be designed to display as much or as little information as a study's data analysis needs.

Timelines are 'an organized display' (Gill *et al.*, 2010) of large quantities of complex information about a patient and could be designed to display as little or as much information as a study required. They are a useful technique to add to the health services research toolbox.

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References

- Bui, A.A., Aberle, D.R., McNitt-Gray, M.F., Cardenas, A.F. and Goldin, J.** 1998: The evolution of an integrated timeline for oncology patient healthcare. *Proceedings of the AMIA Symposium* 165–69.
- Daly, B., Newton, J.T. and Batchelor, P.** 2010: Patterns of dental service use among homeless people using a targeted service. *Journal of Public Health Dentistry* 70, 45–51.
- Gill, J., Chearman, T., Carey, M., Nijjer, S. and Cross, F.** 2010: Presenting patient data in the electronic care record: the role of timelines. *Journal of the Royal Society of Medicine Short Reports* 1, 29.
- Hayashi, N., Kidokoro, H., Miyajima, Y., Fukazawa, T., Natsume, J., Kubota, T. and Kojima, S.** 2010: How do the clinical features of brain tumours in childhood progress before diagnosis? *Brain Development* 32, 636–41.
- Mactier, H., Mokaya, M.M., Farrell, L. and Edwards, C.A.** 2011: Vitamin A provision for preterm infants: are we meeting current guidelines? *Archives of Disease in Childhood. Fetal and Neonatal Edition* 96, F286–89.
- Murray, S.A., Kendall, M., Boyd, K. and Sheikh, A.** 2005: Illness trajectories and palliative care. *British Medical Journal* 330, 1007–11.
- Nygren, E., Wyatt, J.C. and Wright, P.** 1998: Helping clinicians to find data and avoid delays. *Lancet* 352, 1462–66.
- Plaisant, C., Mushlin, R., Snyder, A., Li, J., Heller, D. and Shneiderman, B.** 1998: LifeLines: using visualization to enhance navigation and analysis of patient records. *Proceedings of the AMIA Symposium* 76–80.
- Treble, T.M., Hansi, N., Hydes, T., Smith, M. and Baker, M.** 2010: Process mapping the patient journey: an introduction. *British Medical Journal* 341, c4078.
- Wilne, S.H., Ferris, R.C., Nathwani, A. and Kennedy, C.R.** 2006: The presenting features of brain tumours: a review of 200 cases. *Archives of Disease in Childhood* 91, 502–506.
- Wyatt, J.C. and Wright, P.** 1998: Design should help use of patients' data. *Lancet* 352, 1375–78.