

Understanding Requirements of Novel Healthcare Information Systems for Management of Advanced Prostate Cancer

Amol S. Waghlikar, *Member, IEEE*, Maggie Fung and Colleen C Nelson

Abstract— Effective management of chronic diseases is a global health priority. A healthcare information system offers opportunities to address challenges of chronic disease management. However, the requirements of health information systems are often not well understood. The accuracy of requirements has a direct impact on the successful design and implementation of a health information system. Our research describes methods used to understand the requirements of health information systems for advanced prostate cancer management. The research conducted a survey to identify heterogeneous sources of clinical records. Our research showed that the General Practitioner was the common source of patient's clinical records (41%) followed by the Urologist (14%) and other clinicians (14%). Our research describes a method to identify diverse data sources and proposes a novel patient journey browser prototype that integrates disparate data sources.

I. INTRODUCTION

The World Health Organisation (WHO) has specified challenges in chronic disease management [1]. A comprehensive approach is required to prevent and control chronic diseases such as prostate cancer. Healthcare Information Systems (HIS) provide a clinical decision support through data collection, aggregation and presentation to the clinicians as well as patients. HIS plays a critical role in providing point-of-care information needs to improve the health services [2]. The effectiveness of HIS in managing acute health care delivery is widely acknowledged [3-6]. However, application of HIS in effective management of chronic diseases particularly at advanced stages of the disease is challenging [7-9]. The challenges are mainly due to lack of clear understanding of the information requirements. We show that this issue can be resolved by a systematic approach to understand the information requirements.

Prostate cancer is the second most frequently diagnosed male cancer in the world. The global statistics on the prostate

Manuscript received March 29, 2012. This work was supported in part by the Collaborative Research Project Grant between the Australian e-Health Research Centre, Commonwealth Scientific and Industrial Research Organisation (CSIRO) and Queensland University of Technology, Australia.

A.S.Waghlikar is with the Australian e-Health Research Centre, ICT Centre, CSIRO, and Brisbane, Queensland, Australia 4029. (Phone: +61-7-3253-3604; fax: +61-7-3253-3690; (e-mail: amol.waghlikar@csiro.au).

M. Fung, is with the Australian Prostate Cancer Research Centre-Queensland, Queensland University of Technology, Brisbane, Queensland, Australia, 4102 (e-mail: Maggie.fung@qut.edu.au).

C. C. Nelson is with the Australian Prostate Cancer Research Centre-Queensland, Queensland University of Technology, Brisbane, Queensland, Australia, 4102 (e-mail: colleen.nelson@qut.edu.au).

cancer show that the age standardized incidence rates in the countries of Oceania, North America and Europe are in the range of 75.2 to 104.2 incidences per 100,000 [10]. In Australia, it is the second most common cancer in men after skin cancer. It is one of the leading causes of death in Australia [11]. It was the most newly diagnosed cancer in 2007 with 19,403 cases diagnosed [12]. It is also estimated that incidence rates of prostate cancer in Australia will continue to increase until 2020 [13]. Due to chronic nature of the disease, it is always difficult to provide accurate information to the care providers. The main difficulty is due to lack of consistency, availability and accessibility of the data sources for clinical information over a period of 15-20 years. The patient records may reside across various data sources during the disease progression of the prostate cancer. It is therefore important to understand the sources of clinical data as a crucial information system requirement for proposing better healthcare information systems.

Due to the chronic nature of the disease with long term survival period, it is difficult to understand the journey of patients who are at an advanced stage. It is also difficult to design an information solution that can bring all the information together. Multi-disciplinary care is a common approach for chronic disease management [14-16]. The application of innovative information technology is a crucial factor for the delivery of integrated health care through Multi-disciplinary Teams (MDT) [17]. We show that understanding of the inherent data sources as well as health delivery process for advanced prostate cancer patients helps in designing innovative HIS.

II. BACKGROUND

An MDT clinic provides an integrated care model for treating advanced prostate cancer [18]. The MDT care model is of particular importance for advanced stages of prostate cancer. The cancer that has spread beyond the prostate gland is considered as an advanced prostate cancer [19]. The disease progression can be described using various treatment points as clinical events that have occurred between diagnosis and the current status of patient's prostate cancer. This research has considered prostate cancer stages from locally advanced until end-of-life care. The prescribed treatments may change at various stages of disease progression.

The advanced prostate cancer patient may undergo several standard clinical treatments such as radiation and chemotherapy. The patients may also use several alternative therapies and over-the-counter medications. It is important to understand care patterns of advanced prostate cancer patients

with alternative therapies and over-the-counter medications. The accurate understanding of patterns of care for advanced prostate cancer is crucial for designing any HIS as it can improve point-of-care information delivery and subsequent clinical decision support.

III. METHODS

A. Consultation with experts

A consultative approach was taken to identify sources of patient record. Interactive discussions were held with approximately ten domain experts including urologists as well as prostate cancer patient support group representatives. These discussions provided insight into the journey of patients with advanced prostate cancer. The consultations with the clinical researchers as well as clinicians resulted into modelling the process of advanced prostate cancer treatment. The design of any health information system depends on the underlying workflow. Figure 1 shows a high level workflow for treatment of prostate cancer.

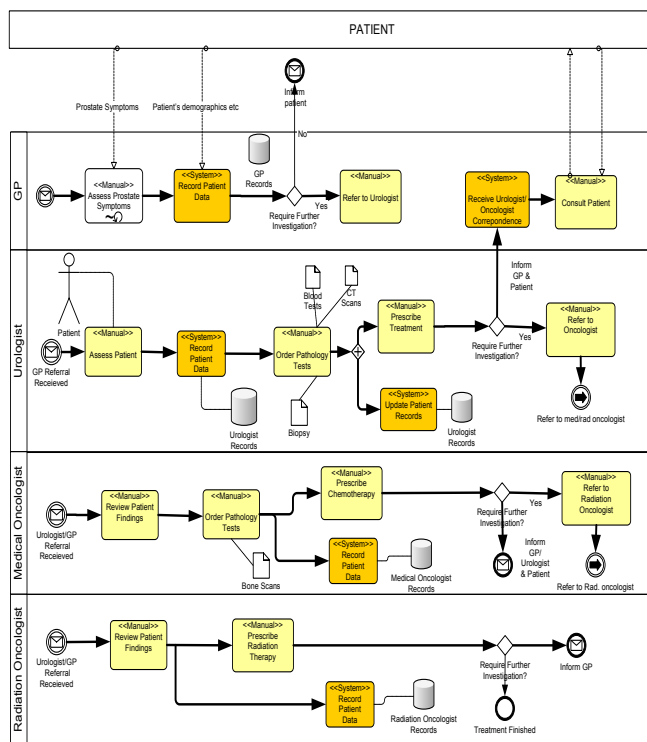


Figure 1. A high level work flow for prostate cancer.

The workflow shown in Figure 1 is described below.

- A patient may experience prostate cancer related symptoms.
- A patient visits a General Practitioner (GP) after an initial diagnosis of prostate cancer. A GP may refer patients to Urologists for further investigation if their blood test or rectal examination is abnormal.
- Urologists may then refer the patients to medical and radiation oncologists for further investigation. They may diagnose the prostate cancer through a biopsy, assess suitability for treatment and provide surgical or hormonal therapy as appropriate.

- Medical oncologists may use new types of chemotherapy that have recently become available for the treatment of advanced prostate cancer.
- Radiation oncologists may use radiation delivered externally with beams or internally with implants such as seeds and rods to treat localised or locally advanced cancer.
- The Urologists and Oncologists inform the GP about the outcomes/ summary of investigations.
- The GP is the centre of information for the patient’s disease and treatment information. The patient records are stored at the GP and patients may also keep a copy of their investigation results and findings.

The investigation about the clinical workflow indicated that there are various clinicians involved in the treatment of advanced prostate cancer. Figure 2 shows various clinicians involved in patient care at various stages of prostate cancer. We have considered the stages: i) Locally advanced prostate cancer; ii) Prostate Specific Antigen (PSA) recurrence following surgery or radiation treatment for localised prostate cancer; iii) Metastatic prostate cancer; iv) Metastatic prostate cancer which has failed androgen deprivation therapy (ADT); and v) End-of-life care. The patient data records reside in different systems (paper-based or electronic) with these clinicians.

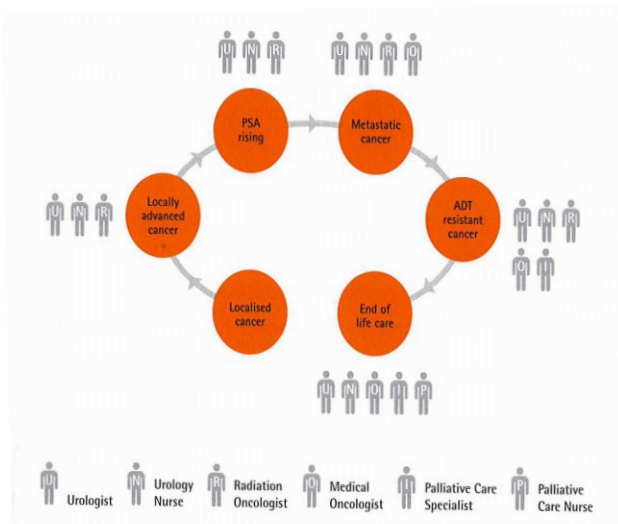


Figure 2. Specialist clinicians involved in different stages of advanced prostate cancer. (Adopted from Cancer Council Australia 2009)

B. Patient Survey

A patient questionnaire was designed to elicit responses from the patients with advanced prostate cancer [20]. The non-identifying questionnaire was designed to understand the heterogeneous sources of patient data. The survey was designed using the categories such as Demographics, Care Provider, Treatment, Hospital Stays, Medications, Alternative therapy or dietary supplements. The questionnaire was distributed to patients through prostate

cancer support groups. The data was collected from August 2010 till December 2010. The data was collected using an on-line version as well as a paper version of the questionnaire. The participation in the questionnaire study was voluntary. A total of 50 patients participated in the pilot study. The data collection from such a large number of patients was challenging. The advanced prostate cancer patients were not easily approachable. Furthermore, many patients did not attend the patient support groups. The data collected in this pilot study was used to answer the following research question about heterogeneous data sources –

1. What are the main data sources of advanced prostate cancer patients during their entire journey?

IV. RESULTS

The results about the sources of clinical records for the advanced cancer patients are shown in Figure 2.

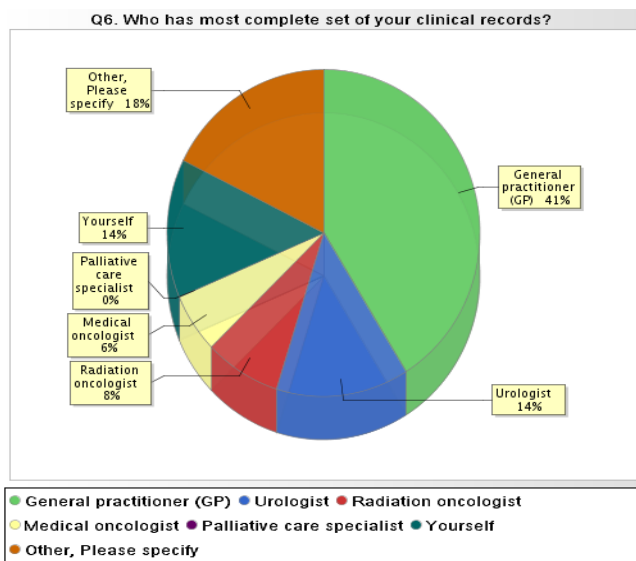


Figure 3. Sources of clinical records.

Figure 3 shows that the most common source of a patient's clinical records is the General Practitioner. The survey findings are described below.

- The GP had the most complete set of patient's clinical information for 41 % of respondents.
- 14 % of respondents indicated that they themselves or their urologist held the complete set of their clinical records.

The clinical information recorded at the primary care provider such as GP or urologists mostly include Prostate Specific Antigen (PSA) level with 96.1 % of responses, digital rectal examination with 66.7 % of responses, biopsy with 78.4 % of responses, bone scan with 72.5% of responses, X-ray with 29.4% responses and other blood tests such as liver function, kidney function with 60.8 % of responses. PSA level is determined in a PSA test as a common screening test for prostate cancer. PSA is a protein produced by the prostate gland cells. The PSA test measures the level of PSA in the blood. A high level of PSA may give useful information about cancer staging [21, 22]. The

patient's belief as to who has their medical records is important as it can improve the quality of clinical consultation as well as information transparency.

V. DISCUSSION

Total 13 patients responded on paper-based surveys and 37 patients responded to online questionnaire indicating the willingness of patients to use online information system. The results of the survey as well as consultations with the clinical researchers indicated that the data sources for the advanced prostate cancer patients exist in disparate systems. The quality of clinical decision making can be improved if all patient data is aggregated and presented in a single patient record. The aggregation of longitudinal data is challenging for chronic disease management. The data aggregation is difficult due to a lack of consistency of clinical data records over a longer time span. The patients may also change their care providers during their disease progression thus limiting the data sharing among their care providers. However, data sharing is critical for better point-of-care information needs. The constraints in data sharing can be addressed by consent between the patient and the care providers. A personally controlled electronic health record may be used to address such challenges.

The other trend that we observed is that the patients maintain their data themselves. Therefore HIS should be able to accommodate self-reported data by the patients. A health information system that can integrate GP records with urologists' records and present an aggregated data to the MDT clinicians is an effective health informatics solution. An integrated system that can browse through the patient journey can improve the efficiency in providing point-of-care information access to the advanced prostate MDT. Based on the findings of this report, the Figure 4 shows the schematic of our proposed patient journey browser system

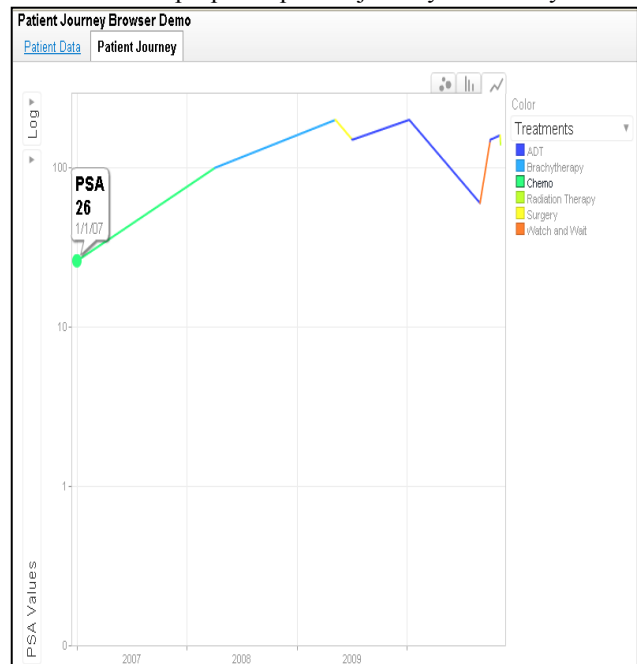


Figure 4. Proposed Patient Journey Browser

The proposed systems can integrate data from various care providers as well as patients. The proposed prototype was developed using motion charts and it shows a dynamic visual of the patient's disease progression. The proposed browser is designed to show a high level visualization of the patient's disease progression through a central parameter. The PSA level determined at various time intervals is the main parameter used to measure the disease progression. The proposed prototype has the ability to visualize the patient data that have been retrieved and recorded from various sources systems. The patient clinical records from the various source systems at the Urologist, Oncologists and other care providers can be used for visualizing the patient journey. The visual data presentation is based on the changing values of PSA levels over a given period in a line graph on a logarithmic scale. Other key information such as current treatments and medications are displayed on the patient journey visual. The data visualization enables clinical decision support at the MDT meetings. The visualization adds crucial value to the clinical decision making process.

CONCLUSION

This research has provided valuable insights into requirements of HIS for advanced prostate cancer patients. The requirements identified in this research enable the design of innovative HIS. The study has identified that GP and Urologist records are the main sources of clinical records for the advanced cancer patients. This research has described an innovative patient journey visualization using a central measure of chronic disease progression. The proposed visualization enables clinical decision support in an MDT clinic environment. A basic version of the system is being used by the advanced prostate cancer MDT clinic at a hospital. Further development of the proposed solution for the advanced prostate cancer MDT may be undertaken in the future. This research has described a use case for prostate cancer management. The proposed system can be used for other chronic diseases such as heart disease and other forms of cancer as well. The application of the findings from this research for other chronic diseases remains an area of future research.

ACKNOWLEDGMENT

This research is a collaborative project between the Australian Prostate Cancer Research Centre-Queensland at Queensland University Technology's Institute of Health and Biomedical Innovation and the Australian e-Health Research Centre at CSIRO. The researchers sincerely thank the collaborators of this project for their valuable support. The researchers sincerely thank the Prostate Cancer Support Groups and PCFA for their valuable cooperation in data collection and promotion of the patient questionnaire.

REFERENCES

[1] H. Tunstall-Pedoe, "Preventing Chronic Diseases. A Vital Investment: WHO Global Report", World Health Organization, Geneva, pp 200, 2005, ISBN 92 4 1563001.

[2] W. Hersh, "Editorials: Health care information technology progress and barriers," *Journal of American Medical Association (JAMA)*, vol. 292, no. 18, pp. 2273-2274, 2004.

[3] M. Berg, "Implementing information systems in health care organizations: myths and challenges", *International Journal of Medical Informatics*, vol. 64, Issues 2-3, Pages 143-156, December 2001.

[4] S. Wu, B. Chaudhry, J. Wang, M. Maglione, W. Mojica, E. Roth, S. C. Morton, P. G. Shekelle, "Systematic Review: Impact of Health Information Technology on Quality, Efficiency, and Costs of Medical Care" *Annals of Internal Medicine*, 144.10, 742-752, 2006.

[5] R. Hillestad, Bigelow J, Bower A, et al. Can electronic medical record systems transform health care? Potential health benefits, savings, and costs. *Health Aff (Millwood)*, vol. 24, pp. 1103-1117, 2005.

[6] E. Ammenwerth, S. Gräber, G. Herrmann, T. Bürkle, J. König, "Evaluation of health information systems—problems and challenges", *International Journal of Medical Informatics*, vol. 71, Issues 2-3, pp. 125-135, September 2003.

[7] L. Casalino *et al.*, "External Incentives, Information Technology, and Organized Processes to Improve Health Care Quality for Patients with Chronic Diseases", *Journal of the American Medical Association* vol. 289, no. 4, pp. 434-441, 2003.

[8] G. Russell, S. Dahrouge, W. Hogg, R. Geneau, L. Muldoon, M. Tuna, "Managing Chronic Disease in Ontario Primary Care: the impact of organizational factors", *Ann Fam Med*, vol. 7(4), pp.309-318, 2009.

[9] J.M. Marchibroda, "The impact of health information technology on collaborative chronic care management", *Journal of Managed Care Pharmacy*, vol. 14(Suppl. 2), S3-S11, 2008.

[10] A. Jemal, F. Bray, M.M Center, J. Ferlay, E. Ward, D. Forman, "Global cancer statistics", *CA: A Cancer Journal for Clinicians*, vol. 61, pp. 69-90, 2011.

[11] Cancer Council Australia, www.cancer.org.au/aboutcancer/cancertypes/prostatecancer.htm, Viewed 24 January 2011.

[12] Australian Institute of health and Welfare, Cancer in Australia 2010: An overview, www.aihw.gov.au/publications/can/56/12138.pdf, Viewed 24 January 2011

[13] Australian Institute of Health and Welfare, "Cancer incidence projections: Australia 2011 to 2020", *Cancer series no. 66*, Cat. no. CAN 62. Canberra: AIHW, 2012.

[14] E.H. Wagner, "The Role of Patient Care Teams in Chronic Disease Management," *British Medical Journal*, 320, no. 7234, pp. 569-572, 2000.

[15] J.E. Jordan, A.M. Brigg, C.A. Brand, R.H. Osborne, "Enhancing patient engagement in chronic disease self-management support initiatives in Australia: the need for an integrated approach", *Med J Aust*, 189:S9-S13, 2008.

[16] Ko. Clifford, S. Chaudhari, "The Need for a Multidisciplinary Approach to Cancer Care", *Journal of Surgical Research*, Vol. 105, Issue 1, Pages 53-57, 1 June 2002.

[17] M. Chiasson, M. Reddy, B. Kaplan, E. Davidson, "Expanding multi-disciplinary approaches to healthcare information technologies: What does information systems offer medical informatics?", *International Journal of Medical Informatics*, vol. 76, Supplement 1, Information Technology in Health Care: Sociotechnical Approaches - ITHC 2004, , Pages S89-S97, June 2007.

[18] Banning, P. Sjøgren, H. Henriksen, "Treatment outcome in a multidisciplinary cancer pain clinic", *Pain*, Volume 47, Issue 2, Pages 129-134, November 1991, ISSN 0304-3959.

[19] Andrology Australia, "Advanced prostate cancer: a guide for men and their families", www.andrologyaustralia.org/docs/Advanced_Prostate_Cancer_Guide_2009.pdf, Viewed 24 January 2011.

[20] Waghlikar A, Fung M, Nelson C. A pilot study on understanding the journey of advanced prostate cancer patients. *Stud Health Technol Inform* 2011; 168:165-71.

[21] M.K. Brawer, "Prostate-specific antigen", *Semin. Surg. Oncol.*, vol. 18, pp. 3-9, 2000.

[22] S. Loeb, W.J. Catalona, "What to do with an abnormal PSA test", *Oncologist*, vol. 13, pp. 299-30, 2008.