The development and implementation of the Northern Health lung cancer digital care pathway: a case study in service change

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ABSTRACT

This case study details the approach utilised to establish an easy to use, accessible and sustainable method for routine collection of Patient Reported Outcome Measures for patients newly diagnosed with lung cancer. We sought to enhance communication with patients and their families, particularly around shared decision making, their quality of life and symptoms, as well as the impacts of their care or treatment. We detail the co-design methodology utilised with consumers and healthcare providers to develop and implement a multi-lingual, fully automated digital care pathway which has been proven to be highly impactful and powerful for both healthcare providers working within the service and consumers enrolled within the digital pathway. This innovative initiative has changed the practice of the lung cancer service across a health service. Furthermore, its success has evolved the organisational strategy, to embed 'Outcomes for Impact' across the health service.

Keywords: care, co-design, consumer, digital care pathway, lung cancer, patient centred, patient reported outcomes, value-based healthcare.

Background

Lung cancer is the fifth most commonly diagnosed cancer in Australia and the leading cause of cancer related death.[1,2] In 2022, there were over 14 529 new cases of lung cancer in Australia and it is predicted that 1 in 20 people will be diagnosed by the age of 85 years.[2] Despite the falling smoking rates, the rates of lung cancer are continuing to rise, with the 10-year incidence projected to increase by 44 and 41% among men and women respectively.[3] Despite Australia having some of the best cancer outcomes internationally, the 5-year relative survival rate remains poor at less than 22%, as most diagnoses are made at the advanced stages of the disease.[2]

The growing complexity in the management of patients with lung cancer is creating significant challenges to the implementation of best-practice.[4] The costs related to the failure in monitoring or implementing measures to improve best practice such as human and societal costs are enormous (averaging A$51 944–A$67 689 per case) and are often associated with initial treatment, terminal care and treatment and medication costs.[5,6] In Australia, such complexity in cancer management, diagnosis and staging management pathways could impose the known delays in the diagnosis of lung cancer with disease progression being a potential contributor to a reduced capacity for treatment. The longer timeframe from suspicion to a confirmed diagnosis may also lead to increased psychological distress and a worsened patient experience.[7] There is growing evidence to suggest that diagnostic and digital pathways within medicine have the potential to improve survival, cost of care and the quality of life of patients, and reduce patient distress.[8]

Digital technology has enabled new methods for patient interactions and the development of innovative virtual healthcare models, allowing for a greater focus on value-based healthcare (VBHC).[9–11] In cancer care most virtual and telehealth interventions have focused on serving long distance cancer care and patient education.[12] In a recent scoping

review, it was reported that digital health and telehealth practices can support interdisciplinary collaborations and continuing education for oncology providers with a goal to improve cancer care for patients.[12] These digital and tele-health services are allowing healthcare organisations to reimagine how patient care can be delivered. Digital health strategies introduced within the care pathway have the opportunity to provide accessible education, self-management and supportive remote care which enable the patient to help themselves and manage their own healthcare needs.[12,13]

With these ongoing advances in medicine and digital technology, as well as the increasing demand for health services, an aging population, rising healthcare costs and limited resources, there has been an unsurprising emergence of evidence supporting VBHC in which the patient is placed at the centre of their own care.[14] Leading this reform within the state of Victoria is Northern Health, a leading healthcare provider in the rapidly expanding outer north of Melbourne. Serving a diverse community with residents from more than 185 countries, speaking over 107 different languages, the population has a lower income, lower health literacy and higher rates of unemployment than the state average.[15] This case study details the approach taken to co-design, refine and implement with clinicians and consumers, a novel digital care pathway (DCP) across the Northern Health lung cancer service, allowing for the collection and use of patient reported information to provide person focused outcomes and a value-based approach to health care.

The case study – improving the lung cancer service across Northern Health in Victoria

This service improvement established an easy to use, accessible and sustainable method for routine collection of Patient Reported Outcome Measures (PROMs) for patients newly diagnosed with lung cancer. The aim was to enhance communication with patients and their families, particularly around quality of life, symptoms, general wellbeing and the impacts of their care or treatment to provide a patient centric approach to care, meeting the needs of our patients.

Following a three-phase approach we: (1) established a clinical steering committee, (2) developed a co-designed fully automated DCP with healthcare providers and consumers and (3) implemented a lung cancer DCP into standard of care.

The lung cancer clinical steering committee comprised six interdisciplinary staff with direct clinical involvement within the service. The steering committee was established to generate an understanding of the knowledge, skills, barriers and expectations for the current care pathway and how the future DCP could provide a more efficient and effective person-centred approach to care. The information gathered from the steering committee informed the content and mode of delivery of the DCP through co-design with clinicians and consumers.

To develop, refine and implement the DCP, a co-design methodology with clinicians and consumers with lived experiences was adopted. A co-design working group was established with two clinicians and six consumers engaged across the design, development and implementation phase of the methodology to ensure the DCP was developed with the end user not just for the end user. Three virtual co-design ideas workshops occurred with in-depth e-communications between meetings. The first ideas workshop assessed the generative research gathered from the steering committee identifying common problems, barriers, perceptions and level of knowledge and understanding of care pathways and strategies among end users. This information informed the content and mode of delivery of the DCP. The second workshop reviewed and refined the co-designed DCP utilising a Delphi process to ascertain the majority of agreement.[16] It is important to note that the PROMS presented to the co-design working group and later included within the DCP included the International Consortium for Health Outcomes Measurements standard lung cancer sets (EORTC QLQ-C30, EQRTC QLQC-LC-13 and ECOG).[17] The third workshop tested, modified and finalised the innovative DCP from end to end to ensure the pathway met the needs of both the healthcare providers and the consumers.

Once developed, refined and tested by the co-design working group, the lung cancer DCP was reviewed by Northern Health Standards Committees to ensure all governance requirements (clinical, medicolegal, and cyber security) were met.

The value of co-design and the voice of our consumers

When developing the DCP with our consumers it was interesting to fully understand their needs especially when developing and implementing the platform within a multi-lingual community. Within our co-design working group we had a Turkish gentleman who, when asked about the delivery of SMS or email, stated:

> I love that you are sending me these messages in Turkish but my daughter will need to help me and she went to school in Australia, she can't read Turkish so I need to be able to change the language back to English. (Patient A)

Without these insights the platform would not have been inclusive for our patients and their caregivers.

The implementation of the lung cancer DCP into standard care

A multi-lingual, fully automated cloud-based health outcomes platform was launched within the lung cancer service

in March 2023. The pathway is accessible in the top five languages spoken by patients in the service, which include English, Arabic, Greek, Turkish and Italian, and can be accessed by SMS, email and QR code. To ensure useability of the platform by both healthcare providers and consumers, training and education was provided to all users on enrolment. The DCP is fully integrated into the Northern Health IT system and has inbuilt analytics and data visualisation tools to help reduce the friction of use from our healthcare providers. When enrolling a patient, the healthcare provider can enter the patient's unique identifiers and all other demographic data is automatically populated from the Patient Administration System. Furthermore, the integration with the Patient Administration System means that when death of the patient is flagged, the patient is automatically discharged from the DCP reducing the risk of inappropriate SMS and emails being sent to families of deceased participants. Given the poor prognosis of patients with lung cancer this automatic dicharge is particularly important. On enrolment into the DCP patients receive a welcome video and a shared decision-making video, and then they complete their baseline surveys. Once their treatment disposition is determined they are allocated their treatment track and complete PROMS and the Patient Activation Measure (PAM-10) (Insignia Health) quarterly for the first year and then annually (Fig. 1). The PAM-10 is a patient activation measure questionnaire which helps clinicians to understand a patient's knowledge, skills and confidence when managing their own health or health care. The use of the PAM-10 by clinicians allows for tailored treatment discussions at a level the patient can understand.

Since the DCP was launched, 132 newly diagnosed lung cancer patients have been enrolled. Patient participation has been high with PROMs completed at baseline (90%) and 3 months (80%). We have very high rates of participation and satisfaction among those who participate. Eighty-five percent are completing the information electronically (SMS or email). The remaining 15% complete the information by telephone or in person. PAM-10 scores improved by six points (average) with 7-in-10 reporting increased activation (i.e. awareness of the patient's own knowledge of their health or health care) at 3 months. Importantly one-in-five patients have completed in a language other than English. In addition, several patients reported financial strain, particularly when first diagnosed (data that would not have otherwise been captured). As a consequence, a streamlined referral pathway to an oncology social worker and psychologists has been developed. Outcome collection, a key component of VBHC and previously missing, is now routine in the lung tumour stream with patients identified and enrolled by the lung cancer nurse in clinic. The integration of PROMs with the scanned medical record has seen high clinician uptake as PROM reports are automatically uploaded on completion to clinic notes.

How the DCP is helping to monitor and care for lung cancer patients – Stephanie's story

Although only launched 9 months prior to this report, the DCP has had a significant impact on the way in which our patients receive care. One such patient example is the story of Stephanie (Fig. 2). Aged 77 years, with stage IIIB lung cancer, at presentation Stephanie had poor lung function and performance status. She was referred for best supportive care and enrolled onto the lung cancer DCP. As part of the DCP, Stephanie completed the PROMs information. When seen at 3 months her condition was stable. Following her
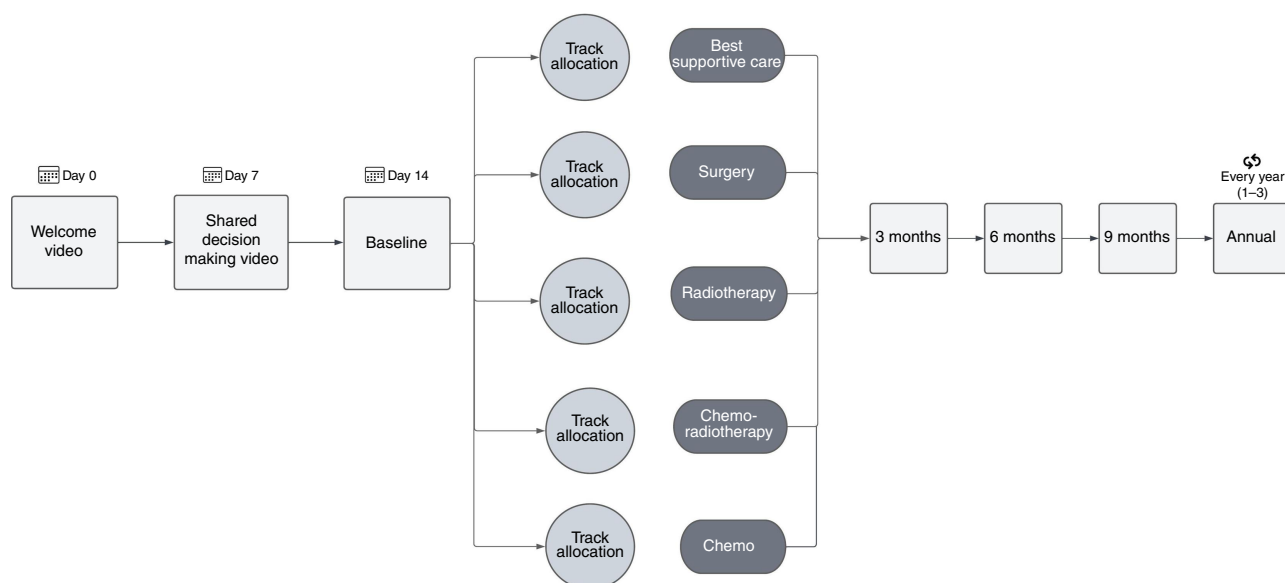
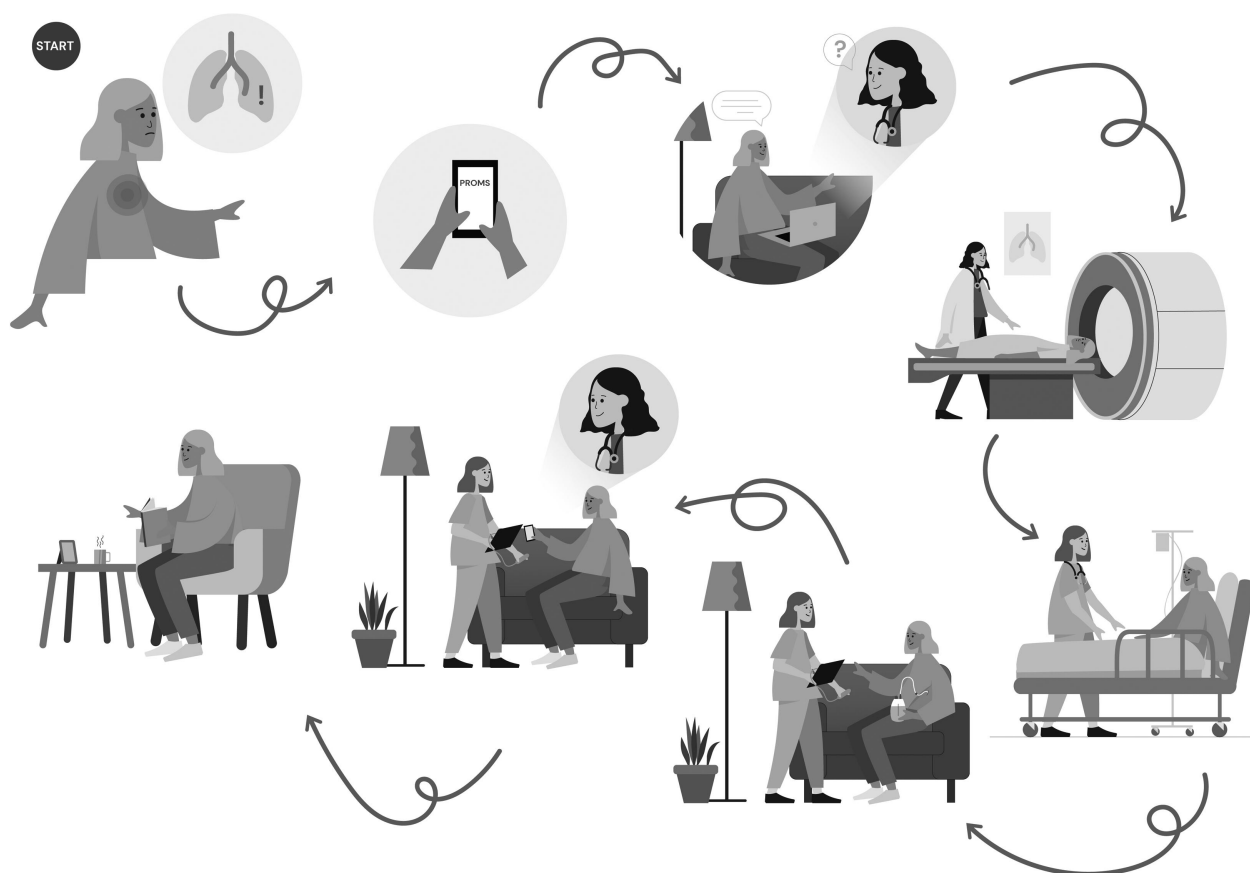

Fig. 1. A schematic of the lung cancer DCP.

Fig. 2. A story board diagram of Stephanie's story, a patient enrolled within the lung cancer DCP illustrating how treatment moved from reactive to proactive care.

3-month follow-up she was sent further PROMs to complete that showed she was experiencing breathlessness and chest pain. Through an e-alert her doctor was able to review her symptoms, contacting her immediately to organise an urgent CT scan, which showed she had a moderately large pleural effusion. On the same day, Stephanie had a pleural drainage removing 2.5 L of fluid. She was able to go home the same day with enrolment into the pleural effusion pathway and significant improvement in symptoms. As part of the pleural pathway Stephanie was visited weekly by a pleural nurse who was able to provide remote tele-ultrasound to the pleural doctor within the clinic to assess for re-accumulation of fluid and detect deterioration. By being on the pathway and completing the PROMS Stephanie's medical team helped her to avoid severe symptoms, emergency department presentation and a hospital stay. Her care due to the DCP moved from reactive to proactive, which created value for Stephanie and the healthcare system.

Discussion

This is the first fully automated lung cancer DCP to be implemented within Victoria, Australia. Our preliminary findings indicate high patient compliance and satisfaction. From the perspective of the healthcare providers (although a formal evaluation is underway to quantify these perspectives) the data have shown the DCP to be highly impactful and powerful, and it has changed the practice of the lung cancer service across Northern Health, a major tertiary healthcare provider with high rates of lung cancer. The data provided have helped to focus patient consults offering a personalised and tailored approach to care and avoiding severe symptoms and emergency department presentations.

Despite the positive initial findings to the lung cancer service, through the implementation of this DCP there have been numerous learnings for those who may embark on such an implementation in the future. The key points that were noteworthy during this process include:

- In health service redevelopment, co-design with consumers with lived experience, clinicians and the digital partner is important to uncover insights not otherwise considered.
- There is a need to invest in dedicated project resources to ensure success of the service redevelopment to a digital health solution. This does not require a substantial investment; however, it will allow for the dedication of resources to the project.

- Change management strategies and staff upskilling within redevelopment of care projects is essential to avoid failure of the innovative improvement in care. Fully understanding the model of care within the service improvement can help to navigate the change required.
- The DCP should be accessible and be easy to use for both the healthcare provider and the consumer.
- The implemented DCP should be inclusive and provide a multilingual interface – enabling culturally and linguistically diverse communities that we serve to complete PROMs in their preferred language.
- Consider the most appropriate channel for communication and be mindful of the increased concern of scams when introducing a digital platform. Most of our patients were reluctant to click on links from SMS messages and preferred branded email notifications.
- Data integration and interoperability is important to ensure the data collected can be used for direct patient care. The process may take longer than expected and may delay a project if not completed correctly.

Notwithstanding the challenges faced throughout the development and implementation of this DCP, the initial findings have demonstrated improvements in the healthcare service for both the healthcare provider and the patient. As a result of this initial success Northern Health have launched 'Outcomes for Impact', an organisational strategy embedding outcomes collection across the organisation allowing healthcare providers to identify and focus on what matters most to their patients and the community. The strategy is designed to help connect the healthcare provider with their purpose in health, delivering the outcomes that matter most to the patient. By doing what matters, Northern Health is leading the change in Australia to implement, evaluate and redesign models of care based on evidence to maximise the impact on health outcomes for patients and the community.

Conclusion

This case study has described the methodological approach utilised to implement an automated lung cancer DCP within a culturally diverse tertiary hospital in the rapidly expanding outer north area of Melbourne, Victoria, Australia. Our preliminary findings are positive, with both clinicians and consumers reporting positive outcomes from the innovative approach to care which has focused on placing the patient at the centre of their own health care.

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