



CASE STUDY: LONDON CANCER TAKES A 'DATA LAKE' APPROACH TO TRACKING PATIENTS AND DATA FLOW ACROSS ITS RENAL CANCER PATHWAY

Delivering the right data, at the right time, to the multi-disciplinary renal cancer team in North London's Centre of Excellence (CoE) requires meaningful collaboration, a deep understanding of the cancer pathway and the ability to leverage modern data application development and data processing techniques.

OVERVIEW

In October 2013, London Cancer produced the comprehensive report, "A case for change in specialist cancer services". The report called for a significant reconfiguration of how specialist cancer services are delivered in North London. The recommendations are perhaps best articulated by Professor Kathy Pritchard-Jones, Chief Medical Officer of London Cancer, who commented: "London is a world-class city and every single Londoner with cancer deserves world-class care. But the configuration of our specialist cancer services in too many smaller centres makes it impossible for our clinical teams to do their best for patients. This is frustrating for everyone; we need a paradigm shift, and are convinced by evidence that consolidating complex and specialist cancer services in a small number of world-class specialist centres where all the experts can work together in high volume teams is the way to achieve it. Such teams will also have the capacity to strengthen expertise and access to innovation at local hospitals."

Clinically led by Mr John Hines, the London Cancer Pathway Director for urological cancer, this paper introduces the on-going, collaborative engagement between London Cancer, UCLP, UCLH, The Royal Free and Aridhia Informatics, to deliver a data solution that underpins the renal cancer's CoE implementation of their integrated 62 day pathway.

Essential to the success of a service that spans a network of primary, secondary and tertiary healthcare organisations, is how efficiently and effectively the associated multi-disciplinary team (MDT) operates. Two key requirements for an effective MDT are, first, a clear integrated care pathway that all stakeholders are aligned to, and, second, that the pathway is underpinned by access to the right information at the right time and only to those authorised to view that data. This ensures that data follows the patient across organisational boundaries and promotes collaboration between the specialist cancer centre and the wider group of hospitals with which it needs to engage.

INFORMATICS GOALS OF THE COLLABORATION

- Track and monitor patients at different stages of the cancer pathway.
- Ensure the healthcare team has access to the information it needs while reducing the risks associated with the handover of data between different provider groups.
- Provide the healthcare team with rapid access to MDT treatment decisions.
- Produce clinical outcome metrics to (a) improve the efficiency of patient care along the cancer pathway, (b) assess effectiveness of treatment and (c) demonstrate that care is delivered to a consistently high standard.

RENAL CANCER PILOT SERVICE

The renal cancer CoE was chosen as the pilot service to implement a new approach to managing data flow across multiple organisations. The London Cancer region delivers integrated clinical care across a network of nine NHS Hospital Trusts, serving a population of approximately 3.2 million. Care is delivered in partnership with GPs, hospices, palliative care providers, charities and universities. The overall goals of the re-design are to improve cancer outcomes and patient satisfaction, and to increase clinical trial recruitment.

THE DATA CHALLENGE

From a data and information standpoint, the challenge focused on five areas.

1. Overcoming the difficulty of extracting and linking the data from multiple treatment centres in a form that can be analysed. This required bringing together data from siloed systems in multiple formats across a wide geography and ensuring the information was complete, accurate, and timely.
2. Ensuring that, once the data was integrated, the rules used for its analysis were fit for purpose and “bound” to the 62 day pathway, allowing various user requirements to be delivered. For example, the CoE might need to drill down to patient level data, manage data warnings alerting the user to issues with a patient’s source data, or determine where patients are in the cancer pathway.
3. Enabling users to view the pathway through multiple devices and locations and with a modern application “look and feel”. If visualisation and user experience were poor, these could prove to be barriers to adoption, even though the data is accurate and the rules correct.
4. Making the final solution deliverable as a service that is both extensible and cost effective.
5. Keeping information governance foremost in the design process.

SOLUTION

Through leveraging modern day application and data processing techniques, the solution comprises five building blocks.

Renal Cancer Data Lake

The flexibility of a “data lake” approach differs from that of the point solution or electronic patient record (EPR) approach that healthcare has been used to. The data lake facilitates the capture of data from all sources. The data lake is also built using open source technologies, avoiding vendor lock-in and dramatically reducing the cost of implementation. This approach supports the secondary objectives of the programme which is to make data available for research purposes by identifying a cohort of patients who may be suitable for clinical trials.

Dataset definition and integration

Aridhia defined and openly released a renal data set aligned to national clinical dataset standards (COSD) and approved in collaboration with the CoE's clinical lead. This data set definition facilitates system owners who supply the source data to extract and present their element of the data lake in the correct format, thereby reducing cost and development time by avoiding the need for each of the supporting organisations to build their own definitions.

Flexible Rules Engine

Underpinning any care pathway is a series of rules and associated information which determines how patients move through the different stages of the pathway. These rules are based on national standards and

guidelines, such as Cancer Wait Times, and other de facto processes which are in operation at a hospital trust. For example, renal cancer patients will be in the “treatment” stage in their care pathway once the specialist multi-disciplinary team in charge of their care has determined an appropriate course of treatment and agreed this with the patient. As this information is captured electronically, Aridhia can encode a series of rules which can be executed against the patient's data, thereby determining whether the patient is in the “treatment” stage or still at an earlier stage in the pathway.

The rules engine is therefore a key component of the solution, and can be adapted to renal or any other cancer pathway.

Template Visualisation

Generic visualisations, built by Aridhia using a rapid development technique, keep costs down and are capable of being reused for other cancer types, thereby ensuring the extensibility of the solution and avoiding unnecessary duplication of work.

Information Governance

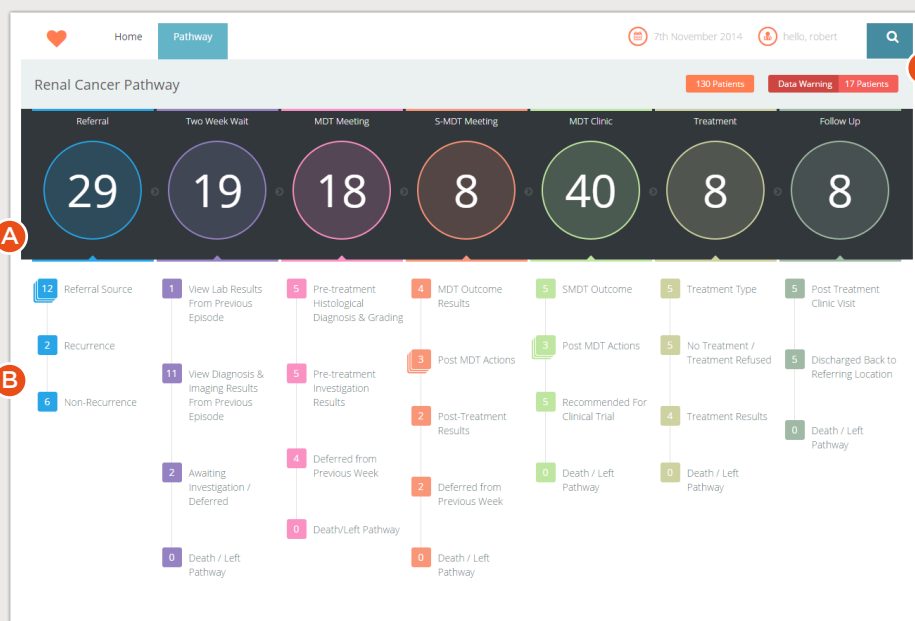
The solution has been designed with inbuilt technical and operational safeguards to help the collaboration meet its obligations under the law, international standards and sector specific standards such as the UK Data Protection Act 1998, the NHS England IG Toolkit, Information Security Standard ISO27001 and the European Data Protection Directive 95/46/EC.

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The pathway gives the user an end-to-end view, allowing the MDT to easily manage patients and workflow.

A/B Each pathway node and sub-node displays the number of patients at each stage.

C Data warnings alert the user to any issues with a patient's source data.



NHS NUMBER	FORENAME	SURNAME	GENDER	DATE OF BIRTH	BREACHED	TIME ON PATHWAY
8745123590	John	Smith	Male	14/08/1986	not reached	74 Days
8745123590	David	Jones	Male	07/02/1991	not reached	23 Days
8745123590	Sarah	Piper	Female	21/02/1974	not reached	31 Days
8745123590	Roger	Spears	Male	05/10/1989	not reached	56 Days
8745123590	Jennifer	Miller	Female	30/05/1954	not reached	63 Days
8745123590	Susan	Dailly	Female	22/04/1987	not reached	20 Days
8745123590	Douglas	Baird	Male	17/10/1963	not reached	19 Days
8745123590	Simon	Greenard	Male	11/12/1978	not reached	61 Days
8745123590	Susan	Dailly	Female	19/12/1997	not reached	14 Days
8745123590	Douglas	Baird	Male	02/01/1971	not reached	85 Days

Selecting any one of the nodes brings up that specific nodes' patient list. This screen shows detail on the patient and their status on the pathway.

Patient Profile
JONES, Stuart
BORN: 17-Oct-1972, GENDER: Male, NHS NUMBER: 1234567890

RENAL CELL CARCINOMA
DATE OF DIAGNOSIS: 19-Sept-2014
SUPPLEMENTARY GRADE: Grade 2
CURRENT STAGE: Stage II

CONSULTANT DETAILS
Dr A Smith
0123 4567890, 017 443, a.smith@email.com

RECENT RESULTS
Imaging: Renal Ultrasound (19-Sept-2014)
Laboratory: Local (19-Sept-2014), Specialists (19-Sept-2014)

TREATMENT TYPE
Curative Surgical: Nephrectomy

PLANNED ENCOUNTERS
S-MDT Clinic (20-Sept-2014)

ALERTS & ALLERGIES
None, Penicillin, Soya

Key Events
Appointments, Pathology/imaging, Imaging, S-MDT Meeting Summary, Treatment Summary, Correspondence, Presence

EVENT	DATE	DAYS ON PATHWAY	BREACH DATE
Date of Referral	01-Sept-2014	0	-
Referral to Treatment Date	08-Sept-2014	7	-
Staging Complete	19-Sept-2014	18	-

The patient profile pages is where the application displays patients' data, collected from multiple data sources and collated into a user friendly interface.

PROJECT STATUS

The collaboration, including the multi-disciplinary team of clinicians, service managers, ICT staff from London Cancer, UCLP, UCLH, The Royal Free and Aridhia, has documented how the renal cancer pathway works across multiple hospital trusts. The clinical dataset which will underpin the application has been defined, as well as

the data sharing agreements which ensure that patient privacy and best practice guidance on information governance is always followed. Rapid application development techniques, which are collaborative by design, have been used to define the pathway visuals and flexible rules engine.

The programme will be in acceptance testing in Q2 2015.

If you require more information please call the specialist team on +44 131 560 1470 or visit www.aridhia.com