



Health Matters Bulletin

BY REBOOT HEALTH CONSULTANCY
&
ADVISORY SERVICES INC.

ISSUE 1, PART 2

- Shared Care Records – Leading The Way With Interoperability
- Accelerating Cost-Effective Translational Medicine Reimbursement

Contributors Reboot Health Consultancy & Advisory Services Inc Founding Partners
Roche & Cerner

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Foreword

Issue 1, Part 2

Welcome to the first edition of the Health Matters Bulletin, a regular publication provided by the Reboot Health Consultancy & Advisory Services Group and our Founding Partners. The Group's Objective is bringing together policy, industry and health leaders to discuss poignant topics in healthcare by creating opportunities and organizing formal, ongoing dialogue, and focused communications on a health innovation topics with specialized Health Matter's subject experts. We invite you to review articles which provoke thought leadership and foster collaboration, catalyze healthcare innovation to optimize the use and deployment of increasingly scarce resources in this country.

- Editors: Alan Low, Greg Spievak, and Howard Waldner,
Reboot Health Consultancy and Advisory Services Inc.

Acknowledgements

Issue 1, Part 2, Article 3

Shared Care Records – Leading The Way With Interoperability

Authored by

Kate Wensley

BA (Hons), Value Lead, UK Client Development

Cerner

Issue 1, Part 2, Article 4

Accelerating Cost-Effective Translational Medicine Reimbursement

Authored By

Dean A Regier

PhD, Senior Scientist, Cancer Control Research, BC Cancer Associate Professor, School of Population and Public Health, University of British Columbia

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Shared Care Records – Leading The Way With Interoperability

The concept of interoperability between health and care providers across a given geography is certainly not a new idea, but perhaps the definition of what we mean and have come to expect from interoperability has evolved. As patients or consumers of health and care services, we have a certain level of expectation that providers will be informed and will know our medical history, whether we are non-smokers, have a penchant for physical activity, or prescribed a list of medications, etc.

The only way they can know this information – whether it has been recorded by the GP, from the visit to the outpatient dermatology three years ago, or collected from the social care referral – is by embracing shared care records and truly sharing pertinent information about a person across traditional health and care boundaries.

The National Health Services (NHS) in England has historically been guilty of bureaucratic boundaries and discrete silos of information. Not only was this hugely inefficient, it can also be unsettling for a patient who is thinking ‘why on earth are you asking me these same questions again?’ However, data liquidity is on the rise – particularly in defined geographies where key stakeholders have come together at a system-level to determine how best to do this.

Two large metropolitan areas of England who have embarked on hugely successful shared care record programmes are The Great North Care Record [<https://www.greatnorthcarerecord.org.uk/>] in the north-east of England as well as OneLondon [<https://www.onelondon.online/>] which, unsurprisingly covers the country’s capital city. These programmes have demonstrated that the technical capabilities to connect data sources is considered the easy part – the challenging part is agreeing to the decision-making process for all contributing parties. By and large, people expect their necessary health data to already be shared between systems and are often quite surprised that this isn’t the default.

Shared Care Records – Leading The Way With Interoperability

London covers 18 acute hospital trusts, 16 community and mental health trusts and around 1500 GP practices and nearly 1900 community pharmacies all contained within 5 Integrated Care Systems (ICSs) that have some responsibility for the distribution of resources and capacity within their parts of London. In east London they have fully embraced the opportunity for shared care records across the patch and have rebranded their local instance of Cerner's HIE as the east London Patient Record (eLPR).

East London Patient Record (eLPR) Connections

Viewing and data sharing:

Homerton University Hospital NHS Foundation Trust
(acute, community services and GPs out of hours)
Barts Health NHS Trust
All five London ICSs
997+ London GPs
East London NHS Foundation Trust (mental health)
North East London NHS Foundation Trust
(mental health and community services)
London Borough of Newham (social care services)
West Essex CCG

Viewing Only:

Tower Hamlets GP Care Group
North East London CCG (community pharmacies)
Barking, Havering and Redbridge University Hospitals NHS Trust
East London NHS Foundation Trust (community services)
Barts Health NHS Trust (community services)
London Borough of Waltham Forest
Partnership of East London Co-operatives (PELC)
Bikur Cholim (IAPT)
Mind (City and Hackney) (IAPT)
Derman (IAPT)
St Francis Hospice
St Joseph's Hospice



As with all health systems, the pressure on the acute service can be very intense. The COVID-19 pandemic has illustrated the need for better system integration and data sharing to alleviate an over reliance on hospital emergency departments and distribute the provision of care more effectively. In England, an initiative was started earlier this year called the Discharge Medicines Service (DMS) whereby NHS hospitals refer discharged patients to the DMS at their local community pharmacy. This service aims to provide extra guidance and support for newly prescribed medicines – utilising the skills of healthcare professionals in the local community where an appointment to visit is not required and that is crucial – offering huge value to vulnerable patients or those otherwise struggling to access services.

Shared Care Records – Leading The Way With Interoperability

Having access to the person's record has been a game changer for community pharmacists allowing them to review important health information and seeing the bigger picture, enabling even basic interactions to be more meaningful and personal.

Raj Radia, chair of the City & Hackney LPC (local pharmaceutical committee) strongly believes that we should consider the person at the centre of everything and to wrap services around them, highlighting the key role that community pharmacy plays. He says, "We're the only health provider easily accessible, yet we're not being utilised. And I think we've got tremendous potential to really grow this."

Radia is a huge advocate for harnessing the potential of the eLPR for community pharmacists to play a key role in the health and wellbeing of the local population. His advice to community pharmacy colleagues would be: "You have to get on board as there is such a wealth of information available. If you're not accessing the eLPR [when interacting with a patient] you are not giving the best care possible for that patient. We are always here to help!"

True transformation relates to a whole-system change across the entire health and care economy that delivers value-based, patient-centric care. Technology is only a small part of the solution - transformation at such scale depends on strong partnerships, common goals, supportive policy, and appropriate data governance and protection models. To deliver real integrated health and care, it should be a fundamental patient right that their data can flow to the appropriate place where it is needed for health or care regardless of provider, vendor or venue.

For more information about the east London Patient Record, see:

<https://www.cerner.com/gb/en/client-achievements/East-London-influences-access-to-shared-records-for-community-pharmacies>

<https://www.cerner.com/gb/en/client-achievements/east-london-a-trusted-proven-health-information-exchange>

By Kate Wensley, BA (Hons), Value Lead, UK Client Development kate.wensley@cerner.com

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Accelerating Cost-Effective Translational Medicine Reimbursement

New drugs – from discovery to regulatory and reimbursement approval – can take an average of 13 years to reach patients, and up to \$1 billion dollars to develop. [1] Only 13% of molecules entering phase I trials ultimately reach patients. This protracted and costly translational medicine pipeline threatens timely patient access to potentially safe and life-extending therapeutics. It puts upward pressure on the patent-protected price of new drugs, thus challenging the economic sustainability of healthcare systems.

The raison d'être of translational medicine research is to accelerate access to new effective and safe health products (diagnostics, imaging tools, therapeutics, and devices). The University of British Columbia's (UBC) Faculty of Medicine has identified the disruption of existing translational medicine processes as a key opportunity to improve the health of British Columbians. Through research and partnerships, the Faculty of Medicine believes that it can help transform the existing translational pipeline to be more efficient, thus improving patient and population health in an equitable and sustainable manner.

The Academy of Translational Medicine

This direction has led to the creation of the Academy of Translational Medicine as a new entity within UBC's Faculty of Medicine. The goal of the Academy of Translational Medicine is to reduce the timeline for translational medicine reimbursement by 50% or more over a 10-year period.

To achieve this goal, the Academy has 4 focus areas: (i) driving research and innovation through our multidisciplinary world-leading capabilities; (ii) creating a culture of connection and collaboration, through addressing silos, enabling transdisciplinary research, and improving the knowledge base; (iii) expanding and amplifying research, through education, seamless collaboration, and leading-edge technology platforms for a shared data commons; and (iv) translation acceleration, through infrastructure and partnerships with health authorities and industry.

These foci have the cross-cutting theme of the need to better develop data standards, analyses, infrastructure, decision frameworks, and partnerships. Realigning focus from one that emphasizes discovery to one that emphasizes discovery and clinical and economic evidence generation for patient and population benefit will be key to translational medicine and the healthcare innovation ecosystem.

Accelerating Cost-Effective Translational Medicine Reimbursement

Open Science and Translational Medicine Reimbursement

Generating evidence alongside discovery can be facilitated through designing healthcare systems that allow timely and time-limited access to new therapies under certain sustainability conditions. These systems will need to integrate biomedical data with all available health information to support real-time clinical decision-making, evidence generation, and intervention evaluation. Such systems should be built upon open science principles so that discovery can be an outgrowth of patient care, and so that researchers from British Columbia (BC), Canada and around the world can leverage data for patient benefit. This can be considered an application of learning healthcare systems and life cycle assessment.

Through the Academy of Translational Medicine and BC Cancer, my program in Open Science and Translational Medicine Reimbursement - is focusing on the design of regulatory and reimbursement life cycle frameworks within learning healthcare systems. This new translation-to-reimbursement framework is called Life Cycle Health Technology Assessment (LC-HTA).

LC-HTA is characterized by the standardization of data collected and analyses needed for the appraisal and re-appraisal of early-stage discovery and technologies, based on real-world evidence that is leveraged against and concatenated with external data holdings. LC-HTA is premised on open science and a learning healthcare system that is iterative and ongoing, with data platforms that aid regulatory and reimbursement decision-making, and in which all stakeholders participate.

The LC-HTA framework below is being piloted through two real-world evidence precision medicine initiatives, including the Canadian Network for Learning Healthcare Systems and Cost-effective Omics Innovation [CLEO], funded by Genome Canada and Genome BC, and Precision Oncology Evidence Development in Cancer Treatment [PREDiCT], supported by Roche and the Canadian Personalized Health Innovation Network.

Accelerating Cost-Effective Translational Medicine Reimbursement

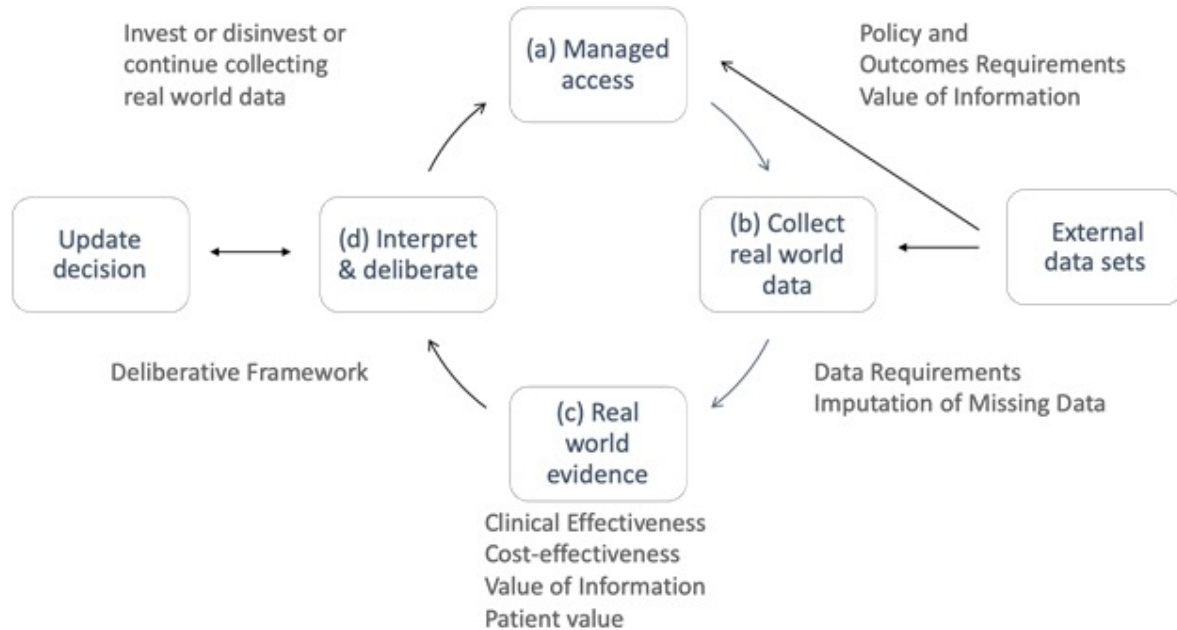


Figure: The life cycle framework is directed to generate and evaluate evidence for: (1) technologies pending regulatory and reimbursement approval, where randomized controlled trial (RCT) evidence is either based on small patient numbers or when RCT evidence will not be generated because of disease rarity or lack of incentivization (e.g., patent expiry); or (2) reimbursed technologies, where there is uncertainty in comparative value, and where technology management is important for sustainability. The components of the framework are: (a) managed access that defines the time horizon and pricing conditions of real-world healthcare system trialing (including zero-cost or discounted cost drug provision); (b) collecting core data elements for real world data, including leveraging external data; (c) real world evidence generation to determine comparative effectiveness, cost-effectiveness (net-benefit), and the value of conducting additional research; and (d) interpretation of data and updating of decisions, including investment, continued evaluation, or disinvestment from managed access.

The need for a real change in precision healthcare is pressing. Current data architecture and curation is not optimized for discovery, translation, and reimbursement; a minority of patients have known driver mutations or actionable conditions, which drives outcome uncertainty; limited and siloed data holdings challenge our ability to generate decision-grade data for real-world evidence; and, regulatory and reimbursement frameworks may no longer be fit for purpose in an age of personalized health. Together, we believe that investing in enhanced data infrastructure, adoption of a life cycle HTA, transparent and comprehensive decision-making policies, and better coordination and implementation between all stakeholders to pursue learning in healthcare can help with the sustainability of our healthcare system.

For more information, see: Canadian Network for Learning Healthcare systems and Cost-effective 'omics Innovation

<https://www.bccrc.ca/dept/ccr/projects/canadian-network-learning-healthcare-systems-and-cost-effective-omics-innovation-cleo>

[PREDiCT: https://www.bccrc.ca/articles/roche-canada-announces-collaboration-improve-access-personalized-healthcare-real-world](https://www.bccrc.ca/articles/roche-canada-announces-collaboration-improve-access-personalized-healthcare-real-world)

<https://mednet.med.ubc.ca/office-of-the-dean/ATM/Pages/default.aspx>

*By Dean A Regier, PhD, Senior Scientist, Cancer Control Research, BC Cancer Associate Professor, School of Population and Public Health, University of British Columbia.
Email: dregier@bccrc.ca, twitter: @deanregier*

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