

Interdisciplinary Informatics to Support Primary Care Sentinel Surveillance of Respiratory Infectious Disease Including COVID-19: Donabedian Evaluation

Carole ASPDEN^a, Sneha ANAND^a, Filipa FERREIRA^a, Gavin JAMIE^a, Rachel BYFORD^a, Mark JOY^a, Simon DE LUSIGNAN^{a,b,1}

^a *Clinical Informatics & Health Outcomes Research Group, Nuffield Department of Primary Care Health Sciences, University of Oxford, UK*

^b *Royal College of General Practitioners Research and Surveillance Centre, 30 Euston Square, London, UK*

Abstract. The Oxford-Royal College of General Practitioners (RCGP) Research and Surveillance Centre (RSC) is one of Europe's oldest sentinel systems, providing sentinel surveillance since 1967. We report the interdisciplinary informatics required to run such a system. We used the Donabedian framework to describe the interdisciplinary informatics roles that support the structures, processes and outcomes of the RSC. Over the course of the COVID-19 pandemic University, RCGP, information technology specialists, SQL developers, analysts, practice liaison team, network member primary care providers, and their registered patients have nearly quadrupled the size of the RSC from working with 5 million to 19 million peoples pseudonymised health data. We have produced outputs used by the UK Health Security Agency to describe the epidemiology of COVID-19 and report vaccine effectiveness. We have also supported a trial of community-based therapies for COVID-19 and other observational studies. The home of the primary care sentinel surveillance network is with a clinical informatics research group. Interdisciplinary informatics teamwork was required to support primary care sentinel surveillance; such teams can accelerate the scale, scope and digital maturity of surveillance systems as demonstrated by the RSC across the COVID-19 pandemic.

Keywords. Medical records systems, computerized; Primary care; COVID-19; Sentinel Surveillance; Information Technology; Pandemics; Vaccine Effectiveness

1. Introduction

The Oxford-Royal College of General Practitioners (RCGP) Research and Surveillance Centre (RSC) is one of Europe's oldest sentinel systems, providing sentinel surveillance of respiratory and other infectious disease since 1967 [1]. The primary focus of the network was influenza and flu vaccine effectiveness, but for the last 30 months its effort

¹ Corresponding Author, Prof Simon de Lusignan, Clinical Informatics and Health Outcomes Research Group (CIHORG), Nuffield Department of Primary Care Health Sciences, University of Oxford, Oxford, OX2 6ED, UK; E-mail: simon.delusignan@phc.ox.ac.uk

has been on the coronavirus-2019 disease (COVID-19) pandemic and COVID-19 vaccine effectiveness [2].

Interdisciplinary informatics is a collaborative, team working process that integrates expertise from multiple disciplines (strictly two or more disciplines) to achieve goals beyond the scope of any of the team's component disciplines. It requires exceptional communication [3].

This paper reports the development of interdisciplinary informatics to enable the development of the RSC, the English national primary care sentinel system to risk to the challenges set by the COVID-19 pandemic.

2. Method

We used Donabedian's classic approach to evaluation reporting the interdisciplinary informatics team that supported the development of structures, process and outcomes associated with the development of the RSC across the COVID-19 pandemic [4].

2.1. Structures and associated team members:

We interpreted "*structures*" as the creation of a new secure network at University of Oxford to replace the previous network at University of Surrey. We report roles associated with creating this infrastructure and extraction of health data from practices.

2.2. Processes and associated team members:

We report what interdisciplinary skills were involved in the new processes had to be developed across the first 30 months of the pandemic.

- We plan with public health specialist from UKHSA how we will enhance surveillance in the coming season including responsive surveillance for any unexpected disease. We require high quality data and virology specimens.
- Data extraction from increasing numbers of primary care providers who joined the RSC; with linkage to hospital admission, intensive care admission, and death data. Pseudonymisation was conducted as close to source as possible and data upload into our SQL server.
- We carefully curated code sets for variables used for surveillance. We also migrated to SNOMED CT and additionally incorporated a series of emergency releases of COVID-19 clinical terms [5].
- Data quality and virology sampling are key processes. We had to introduce a home sampling as it was not appropriate to sample in-practice. We feedback to practices through dashboard and provide observatories to inform policy [6]; plus customised outputs to meet the requirements of the UK Health Security Agency (UKHSA) the national body organising disease surveillance.
- Key data required were: (1) Reliable population denominator, (2) Vaccine exposure data, (3) Capture of disease outcomes: see below.
- We used our surveillance platform to support community-based COVID-19 trials, the most important was the PRINCIPLE trial [7].
- The security of the network had to be developed to ensure legal and policy compliance, in England with NHS Digital's Data Security and Protection policy.

Our plans were also approved by the UKHS Caldicott Guardian under the Health Service (Control of Patient Information) Regulations 2002; Regulation 3 health protection [8].

- Our process were developed in a collaborative way with much international sharing of expertise and experiential learning [9,10].

2.3. Outcomes and associated team members:

The outcomes required were community disease (COVID-19) – before, during, and now after widespread community testing was available. Similarly hospital admission, likely to be COVID-19 related, intensive care unit (ICU), and mortality – where COVID-19 is either listed as a cause of death or occurs within 28 days of a positive COVID-19 test.

3. Results– *Interdisciplinary informatics*

We report how the interdisciplinary informatics team delivering extended surveillance.

3.1. Structures and associated team members:

Information technologists designed and constructed a series of interconnected components to meet the data transfer requirements and fulfil the SQL developers and analysts processing needs, whilst meeting the information governance specialist's requirements. This trusted research environment (TRE), was nominated as a TRE by Health Data Research UK (HDRUK) and given the name "ORCHID" (Oxford-RCGP Clinical Informatics Digital Hub) [11].

3.2. The interdisciplinary team developing a running a range of processes:

The interdisciplinary team included expertise divided into the following eight categories: (1) Public health specialists at UKHSA to specify the service in collaboration with Oxford and RCGP; (2) Information technologists to develop the system hardware based at Department of University level; (3) Data extraction specialist and curators of national dataset to provide data extracts, located in specialist companies, EMIS the largest computerised medical record (CMR) system supplier and NHS Digital; (4) Practice liaison team to sign-up primary care providers to an expanded network, improve their data quality, and encourage to collect virology samples; (5) A data team, predominantly SQL developers who receive, process and pass on data for analysis; (6) Clinical data curators created code sets, phenotypes and ontologies; (7) A research team of analysts and statistician able to analyse these data. Teams 3, 4, 5 and 6 with project managers make up the Clinical Informatics and Health Outcomes Research Group (CIHORG) at Oxford. (8) Clinical trialists organising trials of community interventions in COVID-19 in the Oxford Clinical Trials Unit (CTU) and others. (9) Contractual and information governance (IG) experts to ensure legal and IG standards are met across all organisations.

3.3. Outcomes are the result of complex teamwork:

The outcomes from our primary care surveillance system is as the result of complex teamwork and the practice of interdisciplinary informatics summarized in Table 1, and enabling rapid observation of the epidemiology of COVID-19 and of COVID-19 vaccine effectiveness [12, 13].

Table 1. The breadth of interdisciplinary informatics disciplines supporting Primary care sentinel surveillance

Interdisciplinary Informatics Discipline	Structures	Processes	Outcomes
(1) Public health specialist – UKHSA in collaboration with Oxford & RCGP	Planned to support anticipated infection burden	Responsive COVID-19 surveillance including patient self-sampling	Expanded network (size quadrupled), all year round sampling
(2) Information technologists	ORCHID TRE	Authentication of data & analytics team	Nominated a TRE by HDRUK
(3) Data extraction specialists + National dataset curators	Multiple sources of pseudonymised data	Secure & lossless transfer	Data quality & virology sampling.
(4) Practice liaison team	Manages practice membership Customer relationships management tools	Data sharing agreements (DSA) Dashboards feedback data quality and about virological specimens	Feedback & remuneration
(5) SQL developers	SQL database	Multiple	Data outputs
(6) Clinical data curators	SNOMED code tool	Curation tool	Valid variables
(7) Analyst / statisticians / researchers		Process data	Research outputs
(8) Virology	UKHSA laboratory	Virology	Disease & vaccine monitoring
(8) Clinical trialist	Clinical Trials Unit (CTU)	Recruit practices, provide sampling and outcome data	Trial delivery
(9) Information governance (IG) & contracts	UKHSA Caldicott Guardian, Data Security & Privacy	NHS Digital DSP compliant	Regulation 3 approval, DSP Sign-off

4. Discussion

Organisation of a primary care sentinel network requires interdisciplinary informatics. We manage an end-to-end data process from collection of routine data through to reporting disease incidence and vaccine effectiveness relying on interdisciplinary team work [3]. Developments in informatics, alongside the great use of IT in routine care plus other scientific developments, have enabled the quadrupling of the size of the primary care sentinel network and much more rapid reporting of sophisticated analyses than was previously possible.

This Donabedian evaluation has enabled us to reflect on an interdisciplinary informatics team that developed new structures, particularly the ORCHID TRE [11]; new processes to report on a COVID-19 its outcomes [12, 13].

Traditionally general practice sentinel surveillance is run between primary care, public health and virology experts. However, a clinical informatics and health outcomes research group (CIHORG) delivers the English national primary care surveillance. Interdisciplinary informatics can support the operation of adaptive complex systems.

References

- [1] de Lusignan S, Correa A, Smith GE, Yonova I, Pebody R, Ferreira F, Elliot AJ, Fleming D. RCGP Research and Surveillance Centre: 50 years' surveillance of influenza, infections, and respiratory conditions. *Br J Gen Pract.* 2017 Oct;67(663):440-441. doi: 10.3399/bjgp17X692645.
- [2] de Lusignan S, Lopez Bernal J, Byford R, Amirthalingam G, Ferreira F, Akinyemi O, Andrews N, Campbell H, Dabrera G, Deeks A, Elliot AJ, Krajenbrink E, Liyanage H, McGagh D, Okusi C, Parimalanathan V, Ramsay M, Smith G, Zambon M, Howsam G, Nicholson BD, Tzortziou Brown V, Butler CC, Joy M, Hobbs FDR. Influenza and Respiratory Virus Surveillance, Vaccine Uptake, and Effectiveness at a Time of Circulating COVID-19: Protocol for the English Primary Care Sentinel System for 2020-2021. *JMIR Public Health Surveill.* 2021 Feb 19;7(2):e24341. doi: 10.2196/24341.
- [3] Kuziemyk CE, Borycki EM, Purkis ME, Black F, Boyle M, Cloutier-Fisher D, Fox LA, MacKenzie P, Syme A, Tschanz C, Wainwright W, Wong H; Interprofessional Practices Team. An interdisciplinary team communication framework and its application to healthcare 'e-teams' systems design. *BMC Med Inform Decis Mak.* 2009 Sep 15;9:43. doi: 10.1186/1472-6947-9-43.
- [4] Berwick D, Fox DM. "Evaluating the Quality of Medical Care": Donabedian's Classic Article 50 Years Later. *Milbank Q.* 2016 Jun;94(2):237-41. doi: 10.1111/1468-0009.12189.
- [5] de Lusignan S, Liyanage H, McGagh D, Jani BD, Bauwens J, Byford R, Evans D, Fahey T, Greenhalgh T, Jones N, Mair FS, Okusi C, Parimalanathan V, Pell JP, Sherlock J, Tamburis O, Tripathy M, Ferreira F, Williams J, Hobbs FDR. COVID-19 Surveillance in a Primary Care Sentinel Network: In-Pandemic Development of an Application Ontology. *JMIR Public Health Surveill.* 2020 Nov 17;6(4):e21434.
- [6] Liyanage H, Akinyemi O, Pathirannahelage S, Joy M, de Lusignan S. Near Real Time Feedback of Seasonal Influenza Vaccination and Virological Sampling: Dashboard Utilisation in a Primary Care Sentinel Network. *Stud Health Technol Inform.* 2020 Jun 16;270:1339-1340. doi: 10.3233/SHTI200431.
- [7] PRINCIPLE Trial Collaborative Group. Azithromycin for community treatment of suspected COVID-19 in people at increased risk of an adverse clinical course in the UK (PRINCIPLE): a randomised, controlled, open-label, adaptive platform trial. *Lancet.* 2021 Mar 20;397(10279):1063-1074.
- [8] Taylor MJ. Legal bases for disclosing confidential patient information for public health: distinguishing between health protection and health improvement. *Med Law Rev.* 2015 Summer;23(3):348-74.
- [9] Liaw ST, Kuziemyk C, Schreiber R, Jonnagaddala J, Liyanage H, Chittalia A, Bahniwal R, He JW, Ryan BL, Lizotte DJ, Kueper JK, Terry AL, de Lusignan S. Primary Care Informatics Response to Covid-19 Pandemic: Adaptation, Progress, and Lessons from Four Countries with High ICT Development. *Yearb Med Inform.* 2021 Aug;30(1):44-55. doi: 10.1055/s-0041-1726489. Epub 2021 Apr 21.
- [10] Kissling E, Hooiveld M, Martínez-Baz I, Mazagatos C, William N, Vilcu AM, Kooijman MN, Ilić M, Domegan L, Machado A, de Lusignan S, Lazar M, Meijer A, Brytting M, Casado I, Larrauri A, Murray JK, Behillil S, de Gier B, Mlinarić I, O'Donnell J, Rodrigues AP, Tsang R, Timnea O, de Lange M, Riess M, Castilla J, Pozo F, Hamilton M, Falchi A, Knol MJ, Kurečić Filipović S, Dunford L, Guiomar R, Cogdale J, Cherciu C, Jansen T, Enkirch T, Basile L, Connell J, Gomez V, Sandonis Martin V, Bacci S, Rose AM, Pastore Celentano L, Valenciano M; I-MOVE-COVID-19 and ECDC primary care study teams; I-MOVE-COVID-19 and ECDC primary care study team (in addition to authors above). Effectiveness of complete primary vaccination against COVID-19 at primary care and community level during predominant Delta circulation in Europe: multicentre analysis, I-MOVE-COVID-19 and ECDC networks, July to August 2021. *Euro Surveill.* 2022 May;27(21):2101104.
- [11] de Lusignan S, Jones N, Dorward J, Byford R, Liyanage H, Briggs J, Ferreira F, Akinyemi O, Amirthalingam G, Bates C, Lopez Bernal J, Dabrera G, Eavis A, Elliot AJ, Feher M, Krajenbrink E, Hoang U, Howsam G, Leach J, Okusi C, Nicholson B, Nieri P, Sherlock J, Smith G, Thomas M, Thomas N, Tripathy M, Victor W, Williams J, Wood I, Zambon M, Parry J, O'Hanlon S, Joy M, Butler C, Marshall M, Hobbs FDR. The Oxford Royal College of General Practitioners Clinical Informatics Digital Hub: Protocol to Develop Extended COVID-19 Surveillance and Trial Platforms. *JMIR Public Health Surveill.* 2020 Jul 2;6(3):e19773. doi: 10.2196/19773.
- [12] de Lusignan S, Dorward J, Correa A, Jones N, Akinyemi O, Amirthalingam G, Andrews N, Byford R, Dabrera G, Elliot A, Ellis J, Ferreira F, Lopez Bernal J, Okusi C, Ramsay M, Sherlock J, Smith G, Williams J, Howsam G, Zambon M, Joy M, Hobbs FDR. Risk factors for SARS-CoV-2 among patients in the Oxford Royal College of General Practitioners Research and Surveillance Centre primary care network: a cross-sectional study. *Lancet Infect Dis.* 2020 Sep;20(9):1034-1042.
- [13] Whitaker HJ, Tsang RSM, Byford R, Andrews NJ, Sherlock J, Sebastian Pillai P, Williams J, Button E, Campbell H, Sinnathamby M, Victor W, Anand S, Linley E, Hewson J, D'Arangelo S, Otter AD, Ellis J, Hobbs RFD, Howsam G, Zambon M, Ramsay M, Brown KE, de Lusignan S, Amirthalingam G, Lopez Bernal J. Pfizer-BioNTech and Oxford AstraZeneca COVID-19 vaccine effectiveness and immune response amongst individuals in clinical risk groups. *J Infect.* 2022 May;84(5):675-683.