Lessons from the English primary care sentinel network's response to the COVID-19 pandemic

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This *Comment* reflects our experience of deploying the Oxford-Royal College of General Practitioner's (RCGP) Research and Surveillance Centre (RSC), England's primary care sentinel network, in response to the COVID-19 pandemic.

The RSC is one of the world's oldest sentinel networks, publishing its Weekly Return of contemporaneously monitored conditions since 1967[1], in collaboration with the UK Health Security Agency (UKHSA) and its predecessor bodies. Historically, the RSC comprised 100 nationally representative general practices with a population of around 0.5 million, sharing data, and from 1993 collecting virology samples. For example, the RSC flagged the out of season swine-flu pandemic in July 2009. The RSC grew by 2018 to over 500 practices (N>5 million), further expanding to 2,000 practices (N>19 million) after moving to Oxford prior to the COVID-19 pandemic.[2] The RSC added serological surveillance and asymptomatic virology to its virological sampling of symptomatic patients, each offered by representative subsets of practices. Whilst the focus of the RSC is influenza and acute respiratory infections, it publishes focused reports. These include shingles vaccine effectiveness,[3] and following a recent diphtheria outbreak, the RSC's serosurveillance demonstrated community immunity remains adequate.[4]

The RSC played a major national role during the COVID-19 pandemic, its contributions are summarised in Table 1. Responsiveness, collaboration, and technical innovation underpinned the RSC's pandemic response. Responsiveness included redeployment from other research projects and working with primary care computerised medical record (CMR) system suppliers to create codes that enabled COVID-19 to be recorded. Collaboration with general practice saw the number of RSC practices grow to include coverage of around one-third of England's population.[2] Working with UKHSA, we implemented all year-round virology, direct-to-patient swabs, and a serology programme to investigate population immunity and vaccine waning.[5] Technical innovation included processing new data feeds to create a wide range of novel outputs, including a virology dashboard https://orchid.phc.ox.ac.uk/surveillance/clinical-informatics/virology-dashboard.

At the RSC's core, contemporary data are linked to UKHSA Reference Laboratory virology. The RSC detected the first UK case of COVID-19 not associated with foreign travel, and rapidly reported COVID-19's epidemiology[6] and associated mortality.[7] Early in the pandemic, our serosurveillance demonstrated the population was largely unexposed to SARS-CoV-2 and required vaccination.[8] Complete vaccine exposure data, including brand and batch, were automatically downloaded into primary care CMR systems, as were results from national testing. The UK's system-wide unique identifier (NHS number) enabled individual level registration-based primary care data linkage to rapidly deployed vaccination programme, hospital and death data, and timely national vaccine benefit-risk studies.[9] This model could be rolled out as a low-cost approach across many health systems.

The RSC also provides weekly data to The European Surveillance System (TESSy), belongs to I-MOVE (Influenza – Monitoring Vaccine Effectiveness in Europe) established in 2007,[10] and other international collaborations across primary care, public health, and informatics associations.[11] These collaborations collectively extend the scope and the sharing of data.

Challenges were the shortage of swabs, virology media and personal protective equipment (PPE), along with slow access and charges for linkage to national datasets. The latter were needed for outcome data: hospital and intensive care admissions, and cause of death. Linkage to SARS-CoV-2 variants and the new COVID-19 therapy databases proved impossible. Assessing vaccine risk-benefit

was also limited by the lack of codes (SNOMED Clinical Terms) and poor data quality. Examples include the lack of a long COVID code or single term for thrombosis with thrombocytopaenia syndrome (TTS), making these conditions challenging to reliably identify. We supported research in-pandemic[12] but lacked the infrastructure to recruit study participants at scale.

Key lessons

The RSC's successes were predicated on patients' and general practitioners' willingness to share data, the deep understanding of primary care data by the RSC's clinical academics, its expert processing, and strong relationships with and trust in RSC data by UKHSA.

However, improvements are needed to enable emergent clinical concepts to be coded, permanent linkage to key national datasets, provision of PPE to staff taking specimens, and the capacity and capability of the RSC and its practices to rapidly support research. Whilst the UK has excellent clinical data, there remain data quality issues that require systematic change including allowing sentinel networks to create SNOMED Clinical Terms. The material (swabs, transport medium, PPE etc.) required to support sample collection should be a clear contractual responsibility of one party. Finally, the RSC's pandemic response capability should be regularly tested, spanning the end-to-end process from community sampling to undertaking urgent analyses, to inform the pandemic response. This preparedness should be benchmarked against international standards, such as WHO's Mosaic Framework (https://www.who.int/initiatives/mosaic-respiratory-surveillance-framework) to facilitate international collaboration and convergence.

750 words

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Table 1: Lessons from the RSC deployment in response to the COVID-19 pandemic

Domain	Positive learning – to retain	Lesson learned for future pandemic /outbreaks
Epidemiology of COVID-19 including associated disparities & mortality	1. Direct link to practices (and patient) identified the first UK case with no foreign travel, demonstrating within-community spread, the "Canary in the mine" 2. Introduction of direct-to-patient virology, postage of sample kits to home 3. Serology indicated low levels of community immunity, population vaccination would be needed 4. Rapidly available mortality data, including nursing homes, demonstrated high levels of mortality	1. Better stockpiling of swabs & personal protective equipment is needed; sentinel practices initially had no self-testing 2. Whilst enormous growth in the network size, processing and analytical capability was limited 3. Access to national datasets was slow, and chargeable 4. Scaling issues to support COVID-19 research 5. More rapid recognition of disparities in the impact of COVID-19 6. UK-wide analyses had to be parallel national analyses in the four devolved nations
Vaccine exposure, & effectiveness	1. We reported vaccine exposure, with short lead times 2. We contributed data and undertook vaccine effectiveness studies (national test results were rapid)	1. There were very few vaccine exposure issues only trials and overseas vaccine were not captured 2. National dataset access, for outcomes, was slow
Near real-time vaccine benefit risk	1. Data from primary care record was rapidly available 2. Test results from the national programme were posted into individual's computerised medical records 3. Vaccination data, including brand and batch also automatically recorded into clinical records	1. Codes were not created for important emergent potential vaccine adverse events of interest, including long COVID 2. Lack of access to hospital pathology results 3. Delays or failure to access national data on variants or targeted COVID-19 therapies 4. Primary care data quality – e.g. long COVID
Supporting research	1. Willingness of primary care to support research 2. Rapid access to data, potential for long term follow-up 3. Direct communication to patients through CMR systems	1. Swabs and testing limited support to the PRINCIPLE trial 2. Lack of a rapid, online consent systems for trials 3. Primary care data quality needs systematic improvement

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