The surveillance of systemic cancer therapy access amidst the COVID-19 pandemic: the power of good data

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Of all the shockwaves sustained by health services around the globe following the COVID-19 pandemic, one of the most profound and enduring has occurred in the context of cancer. Regardless of how endemic COVID-19 has been within a given population, cancer services the world-over have had to rapidly adapt and respond to a changing care delivery environment. Each care discipline has faced its own unique challenges, particularly during the on again-off again lockdowns; and in the context of the ongoing provision of systemic cancer therapy, a key hurdle has been disruptions to care access within the usual clinic environment.

Understanding the extent to which COVID-19 has impacted the provision of systemic therapy at a national or regional level would not have been possible in previous decades; but with the growing wealth of health information derived from routinely-collected health data, we were able to gain some clarity on this impact within months of the first lockdowns in early-2020. In New Zealand, Te Aho O Te Kahu, our national Cancer Control Agency, used routine healthcare data to begin reporting on national-level access to first specialist appointments with a medical oncologist, and attendances for intravenous chemotherapy receipt, by May 2020 [1]. Other regions who experienced widespread transmission of COVID-19 have similarly been able to rapidly report on downturns in access to systemic therapy in their respective regions [2-5].

In this issue, Monica Tang and colleagues use national-level data to describe the impact of the COVID-19 pandemic on systemic therapy access in Australia [10.1016/j.lanwpc.2021.100226]. Using data from a substantive sample of the Australian population, the authors were able to show that, although there were initial downturns in the provision of some services during lockdown periods, these setbacks were temporary – with their time series data showing a return to near-normal service provision once the strongest restrictions were lifted. These observations echo those from New Zealand [6], with both countries only lightly impacted by the pandemic relative to others; and perhaps above all else, these powerful data retrospectively illustrate the importance of COVID-19 elimination as prophylaxis against a sustained disruption to the provision of systemic cancer therapy.

The national- or regional-level data reported from Australia, New Zealand, and others are not without their caveats. Firstly, in most regions, access to privately-funded data on systemic therapy receipt are incomplete, which prevents us from building a full picture of national-level access. Secondly, as with all routinely-collected health data, validity relies on the accuracy of clinical coding. Thirdly, there is the issue of data granularity: given that these data are primarily collected for administrative rather than monitoring purposes, variables will usually only reflect the unit of measurement required to ensure that funding is appropriately channelled. As such, some variables can only act as signals for underlying constructs: for example, simply measuring whether a patient attends an IV chemotherapy session tells us nothing of the particular regimen that a patient is receiving, nor whether the treatment has curative or palliative intent.

However, while it is important to recognise these shortcomings – if only to prevent ourselves from over-interpretation – it is equally important that we don’t dismiss the broad observations that can be usefully made based on these data. As was the case in the early months of the COVID-19 pandemic, it is often good enough to be able to tell, at a glance, whether there is something deeply wrong happening within our system. With all the rapid innovations and inherent complexities in systemic therapy, we can sometimes get lost in the detail, and lose sight of the big picture. When a substantially-disruptive national or international crisis strikes, it’s probably most important for us to focus on our broader national cancer control goals: that is, ensuring that treat-
ment is broadly continuing, and that it is doing so equitably across the population.

The usefulness of these signals doesn’t mean that we shouldn’t be constantly trying to improve the quality of the available data. Firstly, it is becoming increasingly unacceptable for private healthcare providers to operate within a country or region and not report care provision to central government. Such reporting is key to the effective surveillance of population-level cancer care, and should be mandatory. Secondly, data collection must be nationally standardised – both in terms of the means by which data are managed (e.g. paper vs. digital records), and the way in which underlying variables are measured (e.g. regimens, cycles, toxicity, etc.). Thirdly, the presence of multiple information technology (IT) systems can prevent the free flow of systemic therapy data between regions, and further complicates centralised reporting; similar to private care providers, IT providers operating within a given region must ensure that their systems can ‘talk’ to existing systems. These (and likely other) factors will both increase the completeness and granularity of the available data, and thus improve the quality of national- and/or regional-level systemic therapy surveillance.

The COVID-19 pandemic has exposed weaknesses in how we provide cancer care amidst crises; from a monitoring and surveillance perspective, it has also exposed weaknesses in our ability to rapidly answer simple questions around treatment access. However, by forcing us to do so, the pandemic has required us to take stock of what information we have at hand, what it can tell us (and what it can’t), and how it can be improved. The resulting improvements in data infrastructure, collection and reporting will enhance our ability to monitor systemic therapy access on an ongoing basis, and increase our readiness for future crises.

Declaration of Competing Interest

The author declares no conflict of interest for this manuscript.

Author contribution

Jason Gurney conceptualised the manuscript, conducted the literature search, and wrote the manuscript.

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