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Collection of routine cancer data from private health-care providers



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The extent to which health care in the UK is funded through private insurance and out-of-pocket expenses has risen over the past 5 years.¹ Chemotherapy delivery and diagnostic endoscopies are the most frequently provided procedures in many parts of the UK.² In contrast to National Health Service (NHS) providers, private providers of cancer care are not mandated to submit data to the National Cancer Registration and Analysis Service, held by Public Health England. For NHS providers, these data include robust information on cancer incidence, stage, and treatments, including surgery, radiotherapy, and chemotherapy. These data support a range of crucial analyses at a national, regional, and provider level informing our understanding of cancer incidence, disease management, and outcomes. Currently,

however, the data following private procedures are not routinely submitted, with limited diagnostic and treatment information available. Given the benefits of the intelligence derived from these data, the increase in private health-care provision and failure to routinely capture information from this sector might have substantial consequences both at a societal and patient level.

From a societal perspective, the identification of a survival gap between the UK and international peers has provided political and clinical motivation to invest in, and deliver, improvements in NHS cancer care over the past two decades. For example, increases in the use of surgery in the treatment of localised non-small-cell lung cancer can, in part, be attributed to previous unfavourable comparisons with international peers.³

For more on the **National Cancer Registration and Analysis Service** see <http://ncin.org.uk/home>

Similarly, for local commissioners and providers, understanding variation in pathways, treatment, and outcomes provides valuable support for targeted improvements in care. In this setting, examples can be seen throughout the cancer treatment pathway, from screening and endoscopy outcomes, early mortality following surgery and chemotherapy, to late toxicity after radiotherapy.⁴⁻⁷ Notably, previous coroner's verdicts in other disease settings have recommended that private providers should "adhere to the same reporting requirements as NHS hospitals";⁸ indeed, following the unexpected death of a patient undergoing cancer surgery, external oversight was recommended to reduce the risk of future deaths.^{8,9}

The *Achieving World-Class Cancer Outcomes: a strategy for England 2015–2020* report¹⁰ by the Independent Cancer Taskforce highlights the imperative to use routine data to support improvements in care and outcomes. Unfortunately, at a national level, as with US-based Surveillance, Epidemiology, and End Results Program data, these analyses will be undermined by an inability to make robust population-level comparisons because of the systematic failure to capture data relating to those treated in the private sector. These effects will only be amplified as care is increasingly delivered within this sector. Conversely, at a provider level, the absence of data will impair the ability of private providers to use robust comparisons to guide improvements in care.

There is, in addition, a current drive to use real-world evidence to support reimbursement decisions, aid pharmaceutical development, and, more broadly, inform wider improvements in health care through digital innovation. Robust data are key to delivering these goals; however, the value of the UK's routine cancer data in achieving this might be undermined by incomplete population coverage. Thus, failure to capture these data might have broad, long-term, economic consequences for both digital and pharmaceutical innovation.

From an individual patient perspective, the decision to receive cancer treatment in the private sector is affected by a range of factors. Practical considerations, such as convenience and the treatment environment, might be of importance in addition to quality of care. It must, however, be recognised that decision making in medicine is characterised by high levels of

information asymmetry; clinicians have substantially greater knowledge of the diagnosis and treatment than do their patients. Therefore, while private provision might offer patients a choice based on their preferences, information asymmetry might hamper their decision making, which will only be exacerbated if routine data are not available to inform patients about the comparative performance of all provider organisations.

The collection of routine cancer data from private providers should now be mandated to prevent any detrimental consequences. Private providers have shown a willingness to embark on the necessary data collection, prioritising publication of performance measures and alignment with NHS data standards.² It is imperative, however, that selective reporting does not render this opportunity as little more than a marketing exercise. Through mandating data collection, existing progress can be built upon, integrating private provider and NHS data, addressing the challenges inherent in this process, and continuing to improve the collection and use of these data across all providers. Patients, clinicians, and commissioners will all benefit: at a societal level, these data will inform the delivery of a world-class cancer service; whereas, at an individual-level, patients can be supported to make informed decisions on the basis of their personal preferences.

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