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Mandating the collection of routine cancer data from private healthcare providers

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The extent to which healthcare in the UK is funded through insurance and out-of-pocket expenses has risen over the last five years.(1) From a cancer perspective, chemotherapy and diagnostic endoscopies are the most frequent privately provided procedures in many parts of the UK.(2) In contrast to 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 undergone, including surgery, radiotherapy and chemotherapy.(3) These data support a range of critical analyses at a national, regional and provider level informing cancer incidence, management and outcomes. Currently, however, the data submitted following private procedures is patchy with limitations to both the diagnostic and treatment information. Given the benefits the intelligence derived from these data offer, the increase in private healthcare provision and failure to routinely capture information from this sector of the healthcare system, may have significant 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 recent 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.(4) 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 in radiotherapy.(5–8) It is notable that previous coroner’s verdicts in other settings have recommended that private providers should “adhere to the same reporting requirements as NHS hospitals”, indeed, following the unexpected death of a patient undergoing cancer surgery external oversight was recommended to reduce the risk of future deaths.(9,10)

The recent “Achieving World-Class Cancer Outcomes – a strategy for England 2015-2020” report 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 SEER data, these analyses will be undermined by an inability to make robust population level comparisons. These effects will only be amplified as increasing levels of care are delivered within the private sector. Conversely, at a provider level the lack of data will limit 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 healthcare through digital innovation. Robust data are key to delivering these goals, however, the value of the UK’s routine cancer data in achieving this may be undermined by incomplete population coverage. Thus, failure to capture these data may have wider, 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 influenced by a range of factors. Practical considerations, such as convenience and the treatment environment may 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 significantly greater knowledge of the diagnosis and treatment than their patients. As such, whilst private provision may offer patients choice based upon their preferences, information asymmetry may hamper their decision-making and can 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 in order to prevent any detrimental consequences. Private providers have demonstrated willingness to embark on this, prioritising publication of performance measures and alignment with NHS data standards.(2) It is imperative, however, that selective reporting doesn't render this little more than a marketing opportunity. 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 all stand to benefit; at a societal level, these data will inform the delivery of a world-class cancer service whilst, at an individual-level, patients can be supported to make informed decisions based upon their personal preferences.

1. Healthcare expenditure, UK Health Accounts - Office for National Statistics. Available from: https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/healthcaresystem/bulletins/ukhealthaccounts/2017
2. PHIN - The private healthcare information network. Annual report 2017-18. Available from: https://apicms.phin.org.uk/Content/Resource/210-PHIN_AR-2017-18.pdf
3. National Cancer Registration and Analysis Service - Public Health England. Available from: http://ncin.org.uk/home
4. Walters S, Benitez-Majano S, Muller P, Coleman MP, Allemani C, Butler J, et al. Is England closing the international gap in cancer survival? Br J Cancer. 2015 Sep;113(5):848–60.
5. National Prostate Cancer Audit - Annual report 2018 outlier communications. Healthcare Quality Improvement Partnership (HQIP); 2019.
6. Wallington M, Saxon EB, Bomb M, Smittenaar R, Wickenden M, McPhail S, et al. 30-day mortality after systemic anticancer treatment for breast and lung cancer in England: a population-based, observational study. Lancet Oncol. 2016;17(9):1203–1216.
7. Morris EJA, Taylor EF, Thomas JD, Quirke P, Finan PJ, Coleman MP, et al. Thirty-day postoperative mortality after colorectal cancer surgery in England. Gut. 2011 Apr 12; gut.2010.232181.
8. Burr N, Rutter M, Shelton J, Smith A, Pearson C, Morris E, et al. OTU-027 A study of post colonoscopy colorectal cancer (PCCRC) in england. Gut. 2018 Jun 1;67(Suppl 1): A184–6.
9. Simon-Healey-2018-0378_Redacted.pdf. Available from: https://www.judiciary.uk/wp-content/uploads/2019/05/Simon-Healey-2018-0378_Redacted.pdf
10. Peter-ODonnell-2018-0201_Redacted.pdf. Available from: https://www.judiciary.uk/wp-content/uploads/2018/07/Peter-ODonnell-2018-0201_Redacted.pdf