



# Loss of population data sources when health systems are not responsible for geographically defined populations: implications of the Health and Social Care Act of 2012 in England

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## Abstract

Biomedical health services and health systems research require timely, complete, accurate and accessible data relating to geographical populations in order to facilitate needs assessment and planning of medical care, new medicines and technology. The international trend towards competition and privatisation has largely proceeded as if data generation were immune to market fragmentation and loss of universal coverage. By examining recent reforms to the English National Health Service, the authors show that this is not the case. Routine and population data are products of administrative systems and the nature, completeness and quality of data available to clinical and public health researchers are substantially impaired by market reforms.

Biomedical health services and health systems research require timely, complete, accurate and accessible data relating to geographical populations to assist needs assessment and planning of medical care, new medicines and technology. Data on incidence, prevalence, mortality and survival rates are dependent on a country's public health information system.

However, in England, market-orientated health system reform and government proposals to replace the census, established in 1801, with surveys should set public health alarm bells ringing. Both measures jeopardise the area-based denominators on which public health relies for monitoring equity and inequalities in access to care, treatment and outcomes.

The interplay between area-based population data, information systems and clinical research makes health system and census reform crucial concerns of evidence-based medicine and also WHO policy with respect to universal healthcare. The international trend towards competition and privatisation has largely proceeded as if data generation were immune to market fragmentation and loss of universal coverage. However, this is not the case. Routine and population data are products of administrative systems, so the nature, completeness and quality of data available to clinical and public health researchers will be substantially impaired when markets are introduced and coverage undermined.

National datasets covering the whole population are not available in predominantly private or market health systems such as the USA's.<sup>1</sup> This is because where markets prevail data systems are constructed not on the basis of an area-based geographical population but on the basis of provider units that risk select in order to compete in the market place. Risk selection is always a problem in markets where datasets are often partial,

non-standardised and a byproduct of reimbursement or payment systems. Comprehensive population datasets, on the other hand, are the hallmark of universal public healthcare systems where data systems tend to reflect the governmental duty to provide healthcare for the whole population. Here, patient selection by payers and providers is not endemic and denominators are or should be geographical rather than membership-based or provider-based.<sup>2</sup>

In England, the controversial Health and Social Care Act 2012 removes the responsibility of the Secretary of State for Health to secure and provide comprehensive healthcare for all citizens and with it the geographical organising principle of the English National Health Service (NHS).<sup>3</sup> Contiguous public administrative bodies known as primary care trusts, currently responsible for the healthcare needs of geographical populations, will be abolished and replaced by clinical commissioning groups (CCGs) with the responsibility for buying care on behalf of their membership. The CCG populations have been made up of the patient lists of their constituent general practices which will soon be allowed to enrol patients from anywhere in the country. Local authorities, too, will be given healthcare responsibilities for residents in their area and also have freedom to charge for some services. The combined effect will be to dissolve the principle of a single public body with a responsibility to meet the healthcare needs of the whole population and replace it with a system in which commissioners will be free to choose among patients in order to enrol members. An extended care market will allow providers to mix public and privately funded patients, creating new data problems.

Data collection will deteriorate as a result of these reforms. Before the Act, denominators were derived from area-level census estimates linked to NHS administrative and other data to provide utilisation, treatment, mortality and survival rates that could be standardised to take account of age, sex, ethnicity and socioeconomic status.<sup>2</sup> These long-established area-based datasets facilitated analysis for resource allocation, health inequality and service uptake and outcome monitoring, as well as workforce planning.<sup>2</sup> The reforms will lead to loss of geographical denominators because, like health maintenance organisations in the USA, clinical commissioning groups will no longer have responsibility for all residents in an area, and so it will become more difficult to monitor inequalities. Loss of census estimates will accelerate this process.

Moreover, market reforms will also expand private provision, and we know from experience that some private bodies simply fail to return data, while others

withhold it on the ground that it is commercially confidential.<sup>2</sup> We also do not know what data returns will be required by private providers in the future. Statutory duties can also differ between the public and private sectors. For example, private providers are not currently obliged to submit registrations to cancer registries. The completeness, quality and representativeness of the National Cancer Registry in England, which dates from the 1960s as a voluntary registry and is one of the largest in the world, is not a foregone conclusion.

The recent Mid Staffordshire inquiry into poor standard patient care in an NHS hospital (the Francis report) emphasised the importance of good data 'for supporting the safe and effective care of individual patients' and informing 'the statistics required for clinical audit, performance data, regulatory oversight and public information'.<sup>4</sup> However, increased discretion and the change from block budgets in an integrated system to activity-based hospital payment systems such as the diagnosis-related group (DRG) impair patient and financial data.

DRGs were introduced into the NHS in 2000 in the form of a national tariff or payment-by results (PbR). In 2010–2011, £28 billion was spent on reimbursing providers of NHS-funded secondary care and the government proposes to extend the system to all hospital activity (£66 billion).<sup>5</sup> But the data could be unreliable.

A recent report from the Audit Commission on PbR<sup>6</sup> has shown in general that coded data are a poor reflection of clinical practice and a report by PricewaterhouseCoopers<sup>4</sup> found evidence that 'providers and commissioners are increasingly negotiating prices locally and abandoning the pricing system'. Data that are the product of evasion and avoidance are unreliable.

Data problems arising from an absence of geographical responsibility are well known in low resource countries where most healthcare is privately financed and run. In 2000, WHO's health system assessment framework, which ranked health systems by performance, was based on estimated values for up to 80% of countries, depending on the indicator.<sup>7</sup> Lack of under-five mortality data has seriously hampered evaluation of Unicef's US\$27 million Accelerated Child Survival and Development programme in 11 Africa countries.<sup>8,9</sup>

Surveys and case studies, though useful adjuncts to routine data, are poor substitutes for national datasets. They are extensively used in the global burden of disease (GBD) estimates that serve among other things as a basis for prioritising international aid. However, scientific robustness of the epidemiological case is open to question. For example, a review of scientific sources underpinning global estimates of depression found that

only 40 of the 191 WHO countries were included, including only 3 of the 46 African countries; only 6 of the 40 countries drew data from a nationally representative population, while the three African studies were based on a single village or town; 45% of studies did not meet GBD's own inclusion criteria for study size and 44% did not show a clear method or study design; and only two used estimates of incidence.<sup>10</sup>

Good information is the cornerstone of public health and universal healthcare. Attenuation or abolition of national, universal datasets will render invisible unequal access to England's healthcare system because it will become impossible to monitor access on the basis of need and outcomes at the area level. Population surveillance also underpins health research and its loss can only encourage capture of evidence-based medicine by industry interests to the neglect of public health. Loss of area-based routine and census data undo two centuries of public health progress and reduce our ability to monitor the consequences of market reform.

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