Connected communities

Using routinely gathered data to empower locally led health improvements

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Key messages

- Routinely gathered data can provide evidence of the impact of collaborative interventions that are led by networks of primary care organisations.
- Due diligence must be taken when using amalgamated datasets for secondary use.
- Near-real-time data that compares clusters of primary care organisations might motivate those involved to lead increasingly effective collaborative improvements.

Why this matters to me

In Ealing, we have roles as general practitioners (GPs), Health Network members and Clinical Commissioning Group leaders. From each of these perspectives we want to develop whole system innovations and use existing data to evaluate their impact on healthcare.

ABSTRACT

Data are routinely used throughout the NHS to report on and monitor performance. For example, detailed information regarding hospital episodes is reported via the Secondary Use Services (SUS) programme. Local commissioners use this data to monitor hospital contracts. In primary care, data such as glycaemic control of diabetes patients is extracted from general practice clinical systems to calculate practice payments for the 'Quality and Outcomes Framework' (QOF). We suggest that this routinely gathered data should also be used to help clusters of practices to learn from locally led innovation and to motivate long-term partnerships for

interorganisational health improvement. Following the recent NHS reforms, the number of data sources that could facilitate this is likely to increase in size, variety and complexity. In this paper, we describe some of the existing data sources that could be used to do this; we also describe some of the dangers of using data in this way, and our conclusions about the best way forward.

Keywords: clinical commissioning, evaluating collaborative interventions, medical informatics, NHS reforms, primary care innovation, routinely gathered data, secondary use of data

Introduction

In England, the Health and Social Care Act 2012¹ has led to the creation of Clinical Commissioning Groups (CCGs) with strong leadership from general practice. This has accelerated the movement of care out of hospitals and collaboration between local practitioners. One example of such increased collaboration in north-west London is the Integrated Care Pilot which brings together practices to collaborate for the care of those who are elderly and those who have diabetes.^{2,3} In Ealing, we have built on this model to establish 'Health Networks'. These are geographic areas of practices

serving patient populations of about 50 000 (10–20 practices) – small enough to produce a sense of belonging and large enough to have political influence.²

Data are routinely collected for secondary use throughout the NHS to monitor performance. For example:

- all hospital episodes are reported via the Secondary Use Services (SUS) programme and are routinely used to monitor hospital contracts⁴

- glycaemic control of diabetes patients is extracted from general practice clinical systems and used to decide the level of payment for the 'Quality and Outcomes Framework' (QOF)⁵
- in London, we use RiO as our Child Health Information System which is routinely interrogated to monitor the attainment of vaccination targets.⁶

The Transparency Agenda⁷ has led to the greater availability of databases that hold routinely gathered data. Here, we review some of the emerging data sources. In this paper, we describe our intention to regularly feedback amalgamated data to Health Networks, so that they can learn in near-real-time about their collective impact, and from this improve their plans and become motivated to continue their efforts to improve care.

We have piloted ways to amalgamate data in this way in the Southall Intervention for Integrated Care,⁴ and have learned from the North West London Collaboration for Leadership in Applied Health Research and Care (CLAHRC) that regular feedback of appropriate data motivates project teams.⁸

Potential data sources

In addition to primary data sources we routinely use within the NHS (e.g. SUS, RiO, GP Clinical systems, Exeter, QMAS), there is a proliferation in increasing public amalgamated data sources which can manipulate data to help compare practice performance. These include the following.

- The Association of Public Health Observatories (APHO)⁹ has produced a general practice profile tool, this allows the integration of a number of public datasets and group practices in 10 national 'peer' groups according to a two-step cluster analysis of practice characteristics. This enables a practice to compare its outcomes across a range of domains against national, local borough and peer norms.
- The MyHealthLondon project publishes data across 22 domains for all practices in London.¹⁰ It has an NHS-facing site with an embedded methodology agreed by the Strategic Health Authority, Cluster leads and London-wide Local Medical Committees. The site allows graphs to be made using customised data from customised groups – evaluating the outcomes for a group of practices over time.
- Following the recent restructuring, the Information Centre for Health and Social Care (ICHSC)¹¹ is the official source for data from the

NHS. It provides a wide range of tools, including iView, the Indicator portal and NHS comparators. The range of data published by the ICHSC is increasing and currently includes QOF, payment by results, demography, NHS Outcomes Framework and patient experience.

Risks of using data to compare Health Networks

These new tools are growing in size, complexity and breadth, in line with the current global trend.¹² These can become powerful tools to improve patient care. Using data for purposes other than those for which they were originally intended carries a number of risks.¹³ There are several risks of using data for secondary use to compare Health Networks, in particular.

- Both providers and commissioners habitually use data for performance. Neither is likely to easily recognise that data can be used in a more developmental and empowering way. It will require role modelling, ground rules and repeated reminders.
- Different contexts have different challenges. Deprived areas in particular are known to have high morbidity, and places with a different ethnic mix have different illness profiles. Data needs to be interpreted with the context in which it is generated.
- Motivational bias – the QOF motivates practices to record diabetes care but not all other long-term conditions, skewing the recorded prevalence.^{5,14} Data needs to be interpreted in the light of various motivating factors and considered from different perspectives.
- In small areas, one factor can have a disproportionate effect on the overall quantitative markers for cost and quality (just one sick patient can significantly increase the use of expensive hospital care). Data for larger areas, e.g. Health Networks and whole boroughs need to be compared, drilling down on the outliers, when necessary using qualitative methods.
- Bringing data together from different research studies and databases can give misleading results, because they were set up to answer different questions and will make conclusions from their answers to that question. A study that explores how to help the elderly with diabetes is likely to conclude a need to extend existing services for the elderly; a study that explores how to help diabetes in the general population, stratified for the elderly is likely to conclude a need to extend existing services for

diabetics. Different people from different perspectives must debate their different interpretations of data before concluding policy implications.

- Data drawn from secondary databases can be misleading because of problems with initial data gathering. QOF data, for example, is dependent upon the accuracy of the practice list sizes, which can be highly dynamic in urban areas such as London. Raw data is better than someone else's interpretation of it.
- Data drawn from constantly changing situations can be misleading because of the changing denominator. Because of patients moving on and off the practice list, a practice with a particularly mobile population may have immunised more than 100% of their practice population but still have 10% of children without immunisations, whereas another practice with a more stable population may have immunised 99% and only have 1% without immunisation. Data catches a snapshot of more complex stories-in-evolution.
- Merging datasets where there is little common frame of reference are particularly challenging. An example is looking for a correlation between deprivation data and healthcare outcomes. Social deprivation data is divided into geographical 'lower layer super output areas' (LSOA) by the Office of National Statistics (ONS). Healthcare outcomes data, by contrast, is provided by GPs' surgeries that span various LSOAs. More appropriate than 'triangulating data' (that aims to pinpoint one truth) is the concept of 'crystallisation of meaning from data'¹⁵ – a community considers different kinds of data that reveal different aspects to make sense of the whole issue.
- If these were not enough causes of misleading conclusions from data there is the problem of cause and effect. In a situation where more than a few factors are acting simultaneously, it is impossible to attribute direct cause from an intervention (the reason for the scientist's 'controlled' laboratory where they examine one aspect in isolation of others). This uncomfortable truth about the limitation of discrete observations in complex situations explains why most situations in primary care benefit from multimethod, participatory action research.¹⁶

Conclusion

There are an increasing number of useful data resources available. These data sources can be used to stimulate collaborative improvements in local communities and Health Networks. Those who interpret

comparative data about different Health Networks need to recognise that data does not 'prove' things, instead it merely provides a set of snapshots of complex and co-evolving sets of stories. Feedback of data needs to be regular to see overall trends, and used as 'food for thought' rather than claiming a higher 'proof'. Data should raise new hypotheses and be used to help people learn, and galvanise them to collective action. This is what it means to be a learning organisation,¹⁷ or a Learning Health Network.

ETHICAL COMMITTEE APPROVAL

This work looks at the application of publically available datasets in Health Networks, so did not need ethical committee approval. Ealing Clinical Commissioning Group provided oversight of the work.

CONFLICT OF INTEREST

The authors are paid advisors to the NHS London & GLA "MyHealthLondon" project referred to in the text.

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