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Implementing the English health inequalities agenda: addressing challenges to person-level, cross-sectoral data linkage, access and routine use for local authority public health

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Abstract

Local authorities are central to the implementation of English Integrated Care Systems' health inequalities agendas, embedding public health into population health management planning. They work with partners to deliver a range of 'health determinant' services and facilities for people in a defined geographic area. This work is substantially premised on the use of cross-sectoral data that is linked at the individual level, readily available, longitudinal and contemporaneous. However, multiple challenges exist to such data availability. This paper elaborates upon these challenges to local authority public health systems and their potential solutions.

Keywords

Integrated care partnerships; data sharing; patient and public confidentiality

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Integrated Care Systems (ICSs) were formally established in England as legal entities with statutory powers and responsibilities in 2022 [1]. They are the latest in a succession of National Health Service (NHS) organisational restructuring exercises [2]. With boundaries normally based on hospital catchment populations, ICSs comprise of local partnerships between NHS organisations, local government authorities, voluntary, community or social enterprise (VCSE) sector organisations and other agencies [1], to provide more 'joined-up' services.

ICSs' primary aims extend well beyond health and social care service planning and delivery, to improving public and population health and addressing health inequalities in access, experience and outcomes [3]. Local authorities are central to this new NHS architecture and the effective implementation of the health inequalities agenda, embedding public health and prevention into their plans. They may work with partners, or commission VCSE sector organisations, to deliver a range of 'health determinant' services (e.g. education, housing and planning and waste collection) and facilities for people and businesses in a defined area. The importance of public health systems in protecting and improving a population's health was affirmed during the COVID-19 pandemic, with local areas mobilised to control infection, identify, reassure and support vulnerable communities, and maximise vaccination uptake [4].

This editorial explores impediments faced by local authority public health bodies in implementing the English health inequalities agenda, focussing on challenges to routine cross-sectoral data linkage, access, contemporariness, and use. In doing so, it first briefly describes cross-sectoral data linkage and its importance to the population health management (PHM) approach, before outlining health-related administrative data beyond health and social care, and discussing the types of datasets available to ICSs, and the challenges and potential solutions to cross-sectoral data linkage for local authority public health systems.

Cross-sectoral data linkage and its importance to PHM

PHM is a national programme introduced by NHS England that uses a data-driven methodology, bringing together data to identify specific populations that health and social care systems can prioritise for their services [5]. It gives an understanding of current and future health and care needs, including those arising from the impact of wider health determinants, enabling the design of more joined-up and sustainable services. For example, frequent users of accident and emergency departments can be targeted for preventative interventions to reduce acute admissions [5]. However, such data are not limited to that arising solely from the health and care sector.

Indeed, a population's care needs are premised on the availability of, access to, and use of integrated administrative data across multiple sectors, mirroring the complexity and dynamic effect of wider determinants, which account for 80 percent of a population's health [6]. The full data scope includes those from health care systems (e.g. primary care, emergency care and hospital services), local authority

person-level data on education, housing, employment, welfare, the criminal justice services, and community-based preventative services delivered by the VCSE sector, such as social prescribing. Indeed, there is a growing demand for these datasets to be linked, with proven working examples centred around suicide and the criminal justice system [7], mental health, social care and education [8]. Only a few examples of active cross-sectoral data linkage exist in England. These include The Connected Bradford Whole System Data Linkage Accelerator [9], the Cambridge Child Health Informatics and Linked Data database [10], and the Dundee linked health and social care database [11]. However, it is not entirely clear whether these can be used for the full range of possible analytics, known as 'secondary uses', by their respective local ICSs. Guidance from NHS England lists approximately 34 secondary uses covering descriptive, diagnostic, predictive and prescriptive domains: risk stratification for early intervention and prevention (2), managing finances, quality and outcomes (14), planning, implementing and evaluating population health strategy (7), and undertaking research (11). Thus a variety of uses can be generated, ranging from an understanding of population segments associated with high intensity service use, re-identifying patients at risk of rehospitalization in need of multi-faceted care, and helping and evaluating the impact of new population health and preventative services, care pathways and programmes [12–14], generating precise and robust analysis for effective planning and decision making, and answering questions requiring large sample sizes or detailed data on hard-to-reach populations [15].

Health-related administrative data beyond health and social care

Three categories of data have emerged of key importance for cross-sectoral data linkage:

1. *Socio-economic determinants of health*: Most of these are administrative datasets describing person-level public services delivered by local councils and the VCSE sector, organised in the context of key areas, such as education, employment, housing, social isolation and crime prevention [16].
2. *Protected characteristics*: Acknowledged in the 2010 Equality and Diversity Act [17], these data include age, disability, gender reassignment, marriage and civil partnership, pregnancy and maternity, race, religion or belief, sex, and sexual orientation. In many cases, individuals experience several of these characteristics simultaneously, known as intersectionality [18].
3. *Inclusion health*: Data referring to people who are socially excluded and typically experience multiple overlapping risk factors for poor health, such as poverty, violence and complex trauma. This includes people who experience homelessness, drug and alcohol dependence, vulnerable migrants, Gypsy, Roma and Traveller communities, sex workers, people in contact with the justice system and victims of modern slavery. People belonging to inclusion groups tend to have very poor health outcomes, often much worse than

the general population and a lower average age of death, contributing considerably to increasing health inequalities.

Individuals and families may fall into one or more of these categories, resulting in complex, dynamic interrelationships. These can exacerbate existing population and health disparities, with their singular and collective magnitude changing over time. For example, severe and multiple disadvantaged [19] describes problems faced by adults involved in the homeless, substance misuse and criminal justice systems in England, with poverty almost universal and mental ill-health a common, complicating factor. In addressing this reality, a 'complexity and systems science' lens and associated research methods are being increasingly acknowledged in public and population health intervention research to understand 'real world' effects, beyond use of traditional approaches such as randomized controlled trials which tend to be more linear focused [20, 21].

Types of datasets available to ICSs

A great deal of data from the above three categories are high-level and anonymised in nature and mainly for surveillance purposes only, failing to achieve what in the business context has been referred to as a "transformational level of maturity" [22]. For such data, ICSs currently depend very much upon stand-alone sources, such as:

1. *Propensity scoring tools*: Used for socio-economic population segmentation (e.g. Index of Multiple Deprivation, CACI ACORN and MOSAIC [Experian]), these employ complex assumptions and apportionment formulae to describe socioeconomic rank by geography.
2. *Large-scale surveys, such as Health Survey for England [23] and the Census UK conducted every decade*: These generate useful insights on person and population wellbeing and vulnerability not captured elsewhere but they are at best cross-sectional, measuring point prevalence and limited by their frequency and data anonymisation at source. This latter feature renders them impossible to be linked at the person level with, for example NHS datasets, to explore impact on health care and its demand in real time and over time.
3. *National surveillance dashboards, such as Fingertips (<https://fingertips.phe.org.uk/>)*: These compile and collate the same anonymised datasets above and represent them on dashboards using statistical comparator tools to help councils and their ICSs to benchmark against each other on selected health indicators.
4. *Shared care records*: These are digital infrastructure programmes rolled out at the ICS (or grouped ICSs) level that create integrated patient-level information stored in one area, usually managed by a third-party digital infrastructure supplier. Care providers that typically contribute to an electronic shared care record include general practitioners (GPs), hospitals, community and mental health trusts and council social care. Their main purpose is for 'direct care', which means frontline

clinicians can access real-time identifiable patient-level information via a secure dashboard at the point of care, enabling them to make informed decisions, not only in hospitals and GP surgeries but also in the community. ICSs are also increasingly using them now for PHM purposes, utilising specific dashboards designed for population health intelligence but these are for mainly risk stratification and surveillance purposes [24].

5. *Research databases at the regional level*: Administrative Data Research (ADR) UK is a partnership between the government and academia intended to transform the way researchers access public sector data to enable informed policy decisions to improve people's lives. More recently, Secure Data Environments (SDE), intended as the default way to access NHS health and social care data, are data storage and access platforms that allow approved users to access and analyse data without the data leaving their safe environment.

Challenges and potential solutions to cross-sectoral data linkage for local authority public health systems

Despite the clear need for, and merits of using, cross-sectoral linked data, the level and extent of data and digital infrastructure for PHM in England remains sub-optimal. To the authors' knowledge, none of UK or England national policies, guidance and frameworks adequately describe the relevance or the necessary process and steps for large-scale, cross-sectoral data linkage beyond NHS and social care.

Challenges

The strengths and limitations of the above-mentioned data categories vary. Discussing the ADR and SDE from the perspective of public interest research, Mourby *et al* highlighted the uncertainty surrounding legal powers to share and link data, data protection obligations, systemic delays and the historic public backlash [25]. From the viewpoint of local authority public health departments, there are a number of challenges affecting cross-sectoral data linkage and utilisation:

1. Unlike NHS and social care data, other datasets are periodically updated rather than contemporaneous and real-time. This is a disadvantage in respect to the shorter-term commissioning and planning cycles across local government and the NHS.
2. Aggregated or spatial data are more often available and accessible for data linkage to describe health characteristics for the vast majority of the population, compared with individual-level data that use a unique identifier normally requiring authorization for onward processing.
3. Dataset incompatibility occurs when different datasets from different periods (e.g. spatial- and person-level) are combined for analyses, potentially generating erroneous conclusions.

4. Cross-sectional rather than longitudinal surveys render extrapolating population health need projections problematic given significant time lags since data were collected. Equally, one-off, periodic collected data can also hinder an accurate understanding of morbidity, mortality and service and resource usage in a dynamically changing population (e.g. the socially excluded or at-risk populations), or among discrete cohorts of people.
5. In the context of national data protection legislation, Articles 6 and 9 of the 2018 UK General Data Protection Regulation (GDPR), together with the 2018 Data Protection Act, protect the processing of personal data (S2[1] DPA 2018), prohibiting the use of 'special category' or 'sensitive' data—i.e., data at the individual level—subject to additional privacy measures. Specifically, it forbids its use except in specific circumstances, such as health care management, reducing public health risks and historical research [26]. While the rationale behind these restrictions is understandable—to ensure privacy, confidentiality and prevent exploitation for commercial benefit—it generates a significant challenge for local organisations, particularly councils, for agreeing a common lawful basis for sharing and integrating person-level health determinants data with health and social care service data to understand and improve population health.
6. The Health Research Authority is an extension of the Department of Health and Social Care and advised by the Confidentiality Advisory Group (CAG), an independent body, on research uses, especially around confidential patient information (CPI). Under section 251 of the NHS Act 2006 and its current regulations, the Health Service (Control of Patient Information) Regulations 2002 [27], a temporary, non-mandatory, authorization gateway is opened to permit the use of patients' medical information (e.g. for research), without their consent and without contravening the common law duty of confidentiality.

Provision exists for non-research applications, but they are likely to be more difficult to approve if local ICSs prioritise cross-sectoral data linkage for routine use. More specifically, guidance in England for integrating datasets outside NHS and adult social care, which normally do not contain NHS numbers, does not appear to exist. This creates uncertainty for a large number of non-NHS, non-social care organisations wishing to arrange new data flows to and from the NHS, particularly around the contractual arrangements that need to be in place and the use of CPI to trace NHS numbers within respective safe secure local data environment within the ICS infrastructure. Moreover, it fails to strike an optimal balance between the good of the majority and individual privacy concerns, with the latter routinely superseding the former. Given the increasing importance of the population health as well as complexity and systems science perspective in analytics and research, the scope of the current legislation and its interpretation limits requirements for routine, integrated, person-level data on health determinants,

protected characteristics and inclusion health groups from non-NHS sources not seen as CPI.

Potential solutions

Extending and simplifying routine access and use of the NHS number for data linkage

To address existing data infrastructure limitations, access needs to be improved for broader use by local ICSs, such as tracking public health improvements over appropriate timelines (e.g. monthly or annually, as opposed to every decade like the Census). Although not a panacea [28], serious consideration should be given to using unique personal identifiers such as the NHS number, that can link information for each registered person in the population across multiple data sources. This can apply across all ICS organisations delivering statutory welfare services (e.g. housing, assisted bin collections, disability and other social security payments, weight management, smoking cessation and other health promotion services).

Improving the legal gateway for setting aside common law duty of confidentiality

Regulation 5 of Health Service (Control of Patient Information) Regulations 2002 describes the permission to process data for a range of medical purposes, broadly including preventative medicine, medical diagnosis, medical research, the provision of care and treatment and the management of health and adult social care services. This legislation could be amended to allow local ICPs with established joint data controller arrangements to process for a range of population health improvement purposes, including research involving the three categories of wider health-related administrative data mentioned above. This would allow greater autonomy and improved collaborative working for data access and analytics to mature ICSs. Secondly, greater autonomy and delegated powers should be given to ICPs for oversight and sanctioning routine data linkage and access where there is already a better understanding and awareness of the complex local data architecture and partnership working between local organisations. Given the increasing demand for data linkage, the centralised CAG may struggle with capacity to process and approve multiple requests for cross-sectoral linkage from various ICSs in England.

Reducing public suspicion and risk-averse organisational cultures

While incidents of data breaches are rare, high-profile examples (e.g. from universities, airlines, pension schemes) have increased public suspicion of the retention, use, and vulnerability of personal data [29]. This suspicion has understandably impacted organisational appetite for data sharing, with caution compelling ICP partners to adopt stricter controls over person-level, inter-organisational data distribution rather than embrace the data linkage and sharing necessary to address a population's needs.

The application of stricter controls by ICPs generates three further problems:

- Full data integration is not possible, resulting in data analyses carried out at an aggregated or geographical level (e.g. Lower Layer Super Output Area [30], practice, electoral ward level), generating ecological fallacy.
- Special category, person-level data collection is often duplicated from organisation to organisation in an ICP, particularly in general practice. Opportunities are thereby missed to make data collection more complementary, efficient and minimise waste.
- Further opportunities are missed to test and improve the quality and completeness of special category data across multiple organisations, a key principle of the GDPR.

The COVID-19 pandemic demonstrated not only how efficient and secure access to linked data can support agile and responsive research [31], but also how data linkage is a crucial precondition to identifying unmet needs for essential healthcare services in a timely manner [32]. To unlock the full potential of available data for routine use, the general public must have confidence in how their data is protected and used. There is a greater need for local health systems to adopt a more proportionate approach for data linkage and access during non-crisis times for population health improvement, as well as during health protection crises like COVID-19.

While the elimination of data breaches is impossible, there is a need to test 'reasonable expectations' [33] (i.e., the extent to which a reasonable person should expect the processing of their data in particular circumstances). In this regard, ICPs—who have access to and wish to use available data—should be expected by central government to undertake intensive, regular, patient and public engagement exercises to explain the inherent and manifold public benefits of data sharing, integration and utilisation for secondary uses at the local level. This can improve and reinforce transparency and reassurance on how the latest safe and secure pseudonymisation and de-identification technology can protect privacy and confidentiality, strengthening confidence in how data linkage is achieved, for what purpose, and how it is managed and stored for safe access. Research examples exist (e.g. the RECOVERY trial) where datasets have been linked for trial participants while ensuring data security and quality [34].

Indeed, evidence of the testing of reasonable expectations around data sharing is a compulsory requirement of the CAG application under section 251. This public engagement may not necessarily avert a negative reaction to such data plans, or fully mitigate negative public perceptions regarding the risk of data breaches but would be helpful in building public trust and confidence in local organisations and enhance health information literacy. In those cases where opposition remains, individuals can be educated on the national data opt-out option, introduced in May 2018, enabling patients to opt out from the use of their health data for research or planning purposes [35]. Organisational data custodians, on the other hand, must be made informed partners in the data sharing endeavour, with individual and organisational needs subordinate to those of target populations.

Conclusion

Adopting a complexity and systems science perspective is becoming more crucial for public and population health analytics, including research. The UK, with Canada, Scandinavia and especially Australia [36], have led the way in making population-level, cross-sectoral data linkage more accessible, forging advances in data security, linkage efficiency, researcher-data custodian connections, workforce capacity and lived experience engagement [37]. However, more cross-sectoral data linkage is required to fulfil ICSs' statutory population health improvement expectations and those of their constituent member organisations, including local authority public health. There is no simple solution to addressing these challenges; they involve multiple data providers and regulators engaging in meaningful and difficult discussion of complex issues that have ethical, legal and societal implications. In the post-COVID-19 landscape, with the lessons learnt regarding routine data that is linked at the individual level, readily available, longitudinal and contemporaneous, there is no better time to advocate for the benefits of sharing data for public benefit. If these challenges are not addressed, the role of ICS partnerships to deliver timely population health improvements and reduce health inequalities will be significantly impeded.

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Statement of conflicts of interest

The authors declare they have no conflicts of interest.

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Ethics statement

Ethical approval is not required as this is an editorial expressing the authors' views based on their knowledge and experience. No new primary data was collected from patients or public.

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Abbreviations

COVID-19:	Coronavirus Disease 2019
GDPR:	General Data Protection Regulations
ICP:	Integrated Care Partnership
NHS:	National Health Service

