Lincolnshire Working for a better future		THE HEALTH SCRUTINY COMMITTEE FOR LINCOLNSHIRE	
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Open Report on behalf of Derek Ward, Director of Public Health

Report to	Health Scrutiny Committee for Lincolnshire
Date:	23 June 2021
Subject:	National General Practice Data for Planning and Research - Data Collection

Summary:

The purpose of this report is to provide information on the National General Practice Data for Planning and Research (GPDPR) data collection and local risks.

Actions Requested:

To receive the report from the Director of Public Health and note its content.

Background

NHS Digital is changing the way it collects data from GP practices. Although the changes are predominantly around the process that is used, the issue has caused some concern, with number of articles in the national, local and social media. Following a statement in the House of Commons the implementation date for the new process has been moved from 1 July to 1 September 2021.

Risks

This has raised the profile, and negative perception, of the national programme with GP practices and the public, with the following risks:

- Disruption to the national programme or substantial numbers of patients 'opting out' of data sharing with NHS Digital locally risks the national data flows for primary care (unlike those for other care provision such as hospital, mental health and community heath activity). Data would be unusable for understanding needs, fair and effective service provision and outcomes for the residents of Lincolnshire. Primary care data are an essential part of the picture, for example in understanding equity of service provision for certain cohorts; the stage at which people engage, are diagnosed and are treated for certain conditions; and for identifying 'rising-risk' individuals to allow intervention and prevention activity before a condition or incident presents. This has implications for Lincolnshire County Council and the Director of Public Health in fulfilling their statutory duties to their best abilities; and for Clinical Commissioning Groups to commission and providers to provide high quality, appropriate and effective services for all, making best use of collective resources.
- Increasing concern over data sharing may impact engagement with local programmes and agreements. This includes the vital engagement of GP practices in Lincolnshire's Population Health Management programme, for which agreements are currently with practices for signing after a number of months of collaborative development and information assurance work.

Information on the programme is available from NHS Digital here: https://digital.nhs.uk/data-and-information/data-collections-and-data-sets/data-collections/general-practice-data-for-planning-and-research

Governance and Safeguards

NHS Digital is the national custodian for health and care data in England and has responsibility for standardising, collecting, analysing, publishing and sharing data and information from across the health and social care system, including general practice. All requests for access must be approved by the Independent Group Advising on the Release of Data (IGARD), which includes specialist primary care and ethics members, and for primary care data also by a GP Professional Advisory Group (PAG), with representatives from the British Medical Association and the Royal College of General Practitioners.

What is Changing?

Data held in the GP medical records of patients are used every day to support health and care planning and research in England, helping to find better treatments and improve patient outcomes for everyone. NHS Digital has collected patient data from general practices using a service called the General Practice Extraction Service (GPES) for over ten years and this is being replaced. NHS Digital has engaged with doctors, patients, the British Medical Association, Royal College of GPs, the National Data Guardian and data and governance experts to design the new process, called the General Practice Data for Planning and Research (GPDPR) data collection.

In addition, the GPDPR service will also help to support the planning and commissioning of health and care services, the development of health and care policy, and public health monitoring and interventions (including for example to the Covid-19 pandemic). This is a huge step forward for Local Authority Public Health, who have advocated for better primary care data sharing for many years, and for joined up intelligence and Population Health Management systems. Local Authority Public Health were not able to access primary care intelligence under the GPES process, and with other additional information assurance controls in place it will allow the same data sharing and intelligence opportunities for primary care as there is already provision for in relation to hospital, mental health and community health intelligence. This will address a gap in information that is crucial to understanding need, service effectiveness and health outcomes for all, and implementing prevention and early intervention activities where they are needed.

What Data are Shared?

Record level data are shared about diagnoses, symptoms, observations, test results, medications, allergies, immunisations, referrals, recalls and appointments; including information about physical, mental and sexual health. Data on sex, ethnicity and sexual orientation are also shared to ensure that intelligence can be understood about fair and impartial outcomes for groups of patients by protected characteristics, as required by law, and on the staff who have treated patients to allow identification of patterns of care and outcomes.

Patients' names and addresses are not shared. All other data that could directly identify patients (such as NHS Number, date of birth, full postcode) is not included - replaced with unique codes before the data is shared with NHS Digital — a process called 'pseudonymisation' which means patients will not be identified directly in the data. Written notes, letters, documents, images, data more than ten years old and data not permitted to be shared by GP practices by law will also not be shared.

How are Data Shared by NHS Digital?

NHS Digital collects, analyses, publishes and shares health and care data safely, securely and appropriately as part of their statutory functions.

Data shared by NHS Digital are subject to robust rules relating to privacy, security and confidentiality. Organisations using the data must have a clear legal basis to do so, for health and care purposes and only the minimum amount of data needed to meet the specific purpose is shared. Lincolnshire County Council is one of those organisations. Data are only made available in response to appropriate requests from organisations approved following independent scrutiny by IGARD alongside local organisations' information assurances and controls.

Local Action to Minimise Risk

Local partners have been made aware of the issue and have started to share messages to help ensure the correct information is available to stakeholders, as well as directing enquires to NHS Digital. Communications have been linked up across Lincolnshire County Council and NHS partners to share consistent messages and answers to frequently asked generic queries raised through our individual programmes of work.

A meeting took place with representatives of NHS Digital on 8 June 2021 to share local concerns and encourage improved engagement and messaging locally.

2. Consultation

This is not a consultation item.

3. Joint Strategic Needs Assessment and Joint Health and Wellbeing Strategy

Intelligence generated from both the national data flows, when it becomes available, and the local Population Health Management programme add value to the Joint Strategic Needs Assessment, and allow for more effective, efficient and inclusive health and care service provision.

4. Conclusion

Without the ability to use GP data, which does not identify individuals, in Public Health intelligence and Population Health Management approaches it is not possible to make best use of our collective health and care resources. An understanding of primary care needs, activity, and effective outcomes for all is required to inform prevention, early intervention and commissioning activities.

It is important that individuals are able to make personal choices as to the data that is shared about them and the purposes for which it is used, and there are established mechanisms for this. In respect of the national GPDPR programme it is important that correct information on data sharing, limitations and benefits are shared to minimise negative impacts on our abilities to carry out our statutory duties in respect of planning and delivering effective, efficient and inclusive health and care services locally, and evaluating the impacts of everything that we do.

5. Background Papers

No background papers within Section 100D of the Local Government Act 1972 were used in the preparation of this report.

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