

DHSC review: Use of health data for research and analysis

March 2021

Executive Summary

Patient data collected and stored within health settings should be easily shared across the system. Healthcare professionals must be able to access all relevant patient information, whatever setting they practise in, so that patients can receive the best possible care. This access must include community pharmacy. Responsibility for storing, securing, and maintaining data remains with the commissioned provider, but interoperability of systems should allow appropriate view between clinical environments and practitioners.

Some of the underlying principles that will need to be considered to enable interoperability and access include culture, professional autonomy, and trust, both between different healthcare professionals and between the public and the health system.

Response

We welcome the forthcoming Data Strategy for Health and Social Care and would encourage DHSC and the NHS to maximise the opportunities that data sharing can bring for healthcare professionals, patients, and the public. It is crucial that there is consistency in underlying principles and technical standards to facilitate interoperable and joined up working, while enabling a competitive environment between system providers. It would not be desirable to have siloed approaches and unwarranted local variation, as this can create inefficiencies in the system at a national level and may also exacerbate health inequalities.

In our response, we have outlined how improved use of data will bring benefits in the following key areas:

- Shared patient care facilitated by appropriate access to records
- Evidence based service design
- Visibility of pharmacy care

Enabling shared patient care

The current Covid-19 pandemic has led to a changed mind-set to shared patient care, particularly regarding data. Joint statements by the statutory regulators and the Information Commissioner's Office in early March 2020ⁱ began a cultural change in managing patient data. This pragmatic, and patient-focused approach to supporting care and maintaining confidentiality has already demonstrated benefit to patients.

There is a clear place for robust data sharing agreements and infrastructure facilitating data sharing across the health system. However, the cultural changes witnessed in the last year need to be embedded among clinicians and the supporting administration. A historic lack of trust or misplaced fear of inadvertent breaches of rules and guidelines hampers high quality patient care. Where data sharing is in the best interests of patients, clinicians and providers should feel confident that this is the correct course of action, and then work to ensure that it is secure.

The rapid changes in information sharing, where confidentiality would have previously been cited as a barrier, need to be maintained and enhanced. Sharing examples of good working practice, using a range of settings and providers, will help embed this. This new way of working has demonstrated that sharing data across the system, when clinically appropriate, is key to delivering excellent patient care in the most efficient way.

Example scenario:

After a hospital visit, an elderly patient who had previously been living independently is discharged to a care home. In moving to the care home for the first time, the patient's nominated pharmacy has also changed. This is the first time that the person has been in a care home and it is important that the care home staff have the right information available to ensure that they can deliver the right care. It is therefore crucial that relevant data can be readily accessed and shared between the different pharmacies, the GP, the hospital, and the care home.

Service design

To enable learnings and iteration of service design, an accurate understanding of the care being delivered is required, therefore commissioned services should be designed from a digital first view. Services should be designed to capture outcomes and incorporate this into the wider health and social care environment, so that a collaborative approach to the provision of care can be taken. Anonymised data should be available for external review, in near-real time, creating a collaborative approach to service improvement.

Good care design is underpinned by the existence of a solid evidence-base. While many commissioners strive to include academic literature (where available) into good service design, often there is a lack of robust underlying data. Greater collection and then visibility of population wide data, will lead to better quality care for patients. Data-driven commissioning is essential to ensure that local populations can access the health and wellbeing services they need. Without using data to decide what type of services are needed and where, there is a risk that resources are not used efficiently and that health inequalities are exacerbated.

Visibility of pharmacy care

Community pharmacies are the first port of call for many people accessing healthcare advice and services. Many of the patient interactions that pharmacy teams have on a regular basis go unrecorded or are only recorded on-site at the pharmacy and are not shared with patient records in other settings. Vital interventions on prescriptions, advice given, commissioned services provided, along with the outcomes and self-care support, all form part of the wider picture of a patient's health and can go largely unseen by the wider health service.

There is a considerable data gap with regards to the invaluable healthcare advice and signposting that community pharmacy teams provide to local populations. Better data sharing provides a valuable opportunity to enhance patient care, by enabling healthcare professionals to identify people who may benefit from specific interactions or services. For example, engaging with COPD patients during pharmacy interactions led to a high proportion of COPD patients receiving their flu vaccination. Patients also shared positive feedback that this example of more joined up care made them feel well looked after.

If more information is routinely shared to and from community pharmacy, a greater level of trust and collaboration will be built across the health system. This will lead to more joined up working and thus improve patient experience.

Appropriate access to records

Infrastructure, and national data sharing agreements will need to be in place to facilitate the sharing of clinical information between community pharmacy and other health settings, including general practice, and secondary care.

To enable system interoperability, data must be inputted in a structured format using nationally agreed standards. We welcome the work of the Professional Record Standards Body to develop standards for community pharmacy services to facilitate seamless information sharing with GP systems. While this is a step in the right direction, the service-specific approach taken to date should be broadened. All services commissioned across the health system should be designed such that service outputs are recorded according to nationally agreed data standards so that this clinical information can be shared across the system to improve patient care and health outcomes.

Improving clinical information sharing across the health and social care system will bring benefits for patients and the public, as they won't have to repeat conversations to different healthcare professionals and better-informed clinical decision making will also lead to enhanced health outcomes. Benefits for healthcare professionals include reduced administrative burden in recording information which has already been inputted in another setting, allowing more time to be spent delivering care and thus creating a more satisfying, patient-centered role.

ⁱ <https://ico.org.uk/about-the-ico/news-and-events/news-and-blogs/2020/03/data-protection-and-coronavirus/>