Care without boundaries: the future of information

Mark Davies argues that GPs have a duty not only to make sure patient data is kept safe and used responsibly for individuals but also made available to support populations

By Dr Mark Davies, medical director, Health and Social Care Information Centre and a GP in Yorkshire

As the NHS and social care systems go through a time of unprecedented change, so it is with our information systems. The current changes to the health and social care system are designed to produce two important shifts in influence and power; the first shifts power from providers to commissioners and the second, perhaps more importantly, shift power from the service to citizens. In systems where there are significant shifts in power there are inevitably associated shifts in information and primary care will be no different.

We need to move towards a new era of an integrated information landscape that can support the development of a knowledge culture based as much on maintaining health and well being as providing treatment for illness. The emerging vision is for a unified and free-flowing data landscape, uninhibited by historical boundaries between different services and settings, with patient involvement at its core.

Connecting the network

To achieve well coordinated care we need well-coordinated information, both for individual patient care and to plan care for populations. Further development in interoperability, (such as the ability of systems to move information around without its meaning being compromised) is needed. The continued development of electronic versions of referral, booking, prescribing and discharges will be fundamental to realising the opportunities of modernising our systems. Standards for recording of data and data quality of our records will be an important area to focus on as the data is used in different contexts between different professionals in teams, with patients and carers, and in anonymised form with those planning care.

In order to understand our patients’ journey from one organisation to another we need health information models that replicate the real world. This requires the linking together of different data sources to create a complete end-to-end picture of a patient’s journey. The powers as set out in the Health and Social Care Act allow for this to happen on a national scale, whilst protecting individual patient confidentiality. Regardless of where data originates – be it from primary, secondary or social care - it has a valid part to play is constructing a patients story. Both commissioning and direct patient care can therefore be supported by and connected via this same resource with HSCIC ensuring information not only flows smoothly around the entire network, but is enhanced and developed within strict governance parameters.

The challenges of primary care are changing and our information response needs to change too. My practice for example looks after an increasingly aging population with complex and varying needs, who typically require help from several different services and individuals at any one time. Such complexity not only generates pockets of information, often in silos, it also brings challenges of complex and sometimes unfamiliar clinical problems that we need support to address.

In order to ensure every patient gets the best care, every time an unexplained variation in care can be highlighted and addressed we needs systems that are well-designed to help us meet this challenge.

Grass roots

Change is not just limited to the fluidity of and access to information however. It also needs to reach the very roots of data collection; addressing how information can be effectively used to best serve different health geographies and populations. Fundamentally, this is about building knowledge, while also supporting the transparency agenda and open data movements.

Opening up records to patients is the first step but in time we need to give patients real control of their own records. In this way we will enable a more equitable adult-adult interaction to occur between patients and the service. This will require cultural changes for all involved and the development of health understanding amongst our patients. In this way we will start to see patients as the most important resource of health care delivery as opposed to those who merely consume health care.

We also need to link contextually relevant information
support in real time to both clinicians and patients in such a way that both have easy, timely access to best practice guidance for their particular clinical circumstances.

While the traditional emphasis has often been on measuring the scale of activity - and such facts and figures are of course fundamental to a degree - there needs to be a movement towards more measurement of the actual value of services, treatments and outcomes in both human and financial terms. There is a need for clinicians to have visibility of the resource implications of the clinical decisions they make. It is critical that the timeliness of these data flows improves to make this possible.

With about one per cent of the population consuming about 30 per cent of NHS resource, it is important that we have the data to allow us to target and stratify interventions on both individual and population levels. In order to redesign our care services in sustainable ways that meet the needs of local communities; having access to the records in GP systems, in a way that maintains the confidentiality of individuals, is going to be central. Without this information and therefore knowledge, health and social care commissioners and organisations face an infinite mountain to climb.

**Making the connection**

The potential value of data linkage to this direction of travel is of course enormous. It is absolutely the key to unlocking a vast area of untapped knowledge about the full patient journey; not only connecting information for the first time but presenting it in standardised and meaningful way.

But linkage itself is only possible if information about different services exists and is accessible. While national secondary care information – predominantly Hospital Episode Statistics (HES) - is a relatively mature resource; standardised, national data from the spheres of general practice and community care in particular has been fragmented at best.

The General Practice Extraction Service (GPES), which is managed by HSCIC, has a major part to play in redressing this imbalance. From April, GPES alongside the Calculating Quality Reporting Service (CQRS) will replace QMAS, but this is just one aspect of the service. GPES will be able to extract data from local GP systems across the country and process it, for the first time, into a national, standardised format.

Each individual data request will of course need to be approved by the GPES independent advisory group and is subject to strict information governance and patient confidentiality principles. But by making this information accessible to the NHS and other approved organisations, GPES will not only be a major provider to the linkage arena, but will also support a diverse range of services and initiatives that aim to improve the diagnosis, treatment and prevention of illness.

**In our own hands**

Linking GP data to hospital data is of course only part of the story for many patients. Information from social care and community services usually features within somebody’s individual journey. “Somebody” – or in other words the individual - is the universal thread of course that binds all of these ideas together; and ultimately will determine the extent to which they evolve.

As trusted custodians of patient information, GPs of course have a key responsibility in ensuring data is used for the immediate care of individuals. But they also have vital role in enabling the responsible use of this data to explore the definitive needs of a population and allow for effective planning and resourcing.

As such, a strong consensus needs to develop within our society in recognising that well-founded knowledge is absolutely fundamental to ensuring better care - with a shared sense of ownership and responsibility among clinicians and patients alike. If essential data about everyone’s individual care is securely accessible for essential analysis; this can only be a powerful lever for positive change. Commissioners can base complex decisions on the full story of activity and outcome, rather than partial chapters that only offer a fragmented view. This investment is key if we are to help support the services that we, as individuals, are all likely to need at some point in our lives.

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