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The Digital House of Care: information solutions for integrated care

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The Digital House of Care: information solutions for integrated care

Digital House
of Care

237

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Abstract

Purpose – The purpose of this paper is to describe the development of a digital tool in an English county striving towards a vision of integrated information that is used to underpin an increasingly integrated future of health and social care delivery.

Design/methodology/approach – It discusses the policy context nationally, the origins and implementation of the initiative, the authors' experiences and viewpoint highlighting key challenges and learning, as well as examples of new work undertaken.

Findings – In all, 12 health and care organisations have participated in this project. The ability for local commissioners and providers of services to now understand “flow” both between and within services at a granular level is unique. Costs are modest, and the opportunities for refining and better targeting as well as validating services are significant, thus demonstrating a return on investment. Key learning includes how organisational development was equally as important as the implementation of innovative new software, that change management from grass roots to strategic leaders is vital, and that the whole system is greater than the sum of its otherwise in-silo parts.

Practical implications – Data linkage initiatives, whether local, regional or national in scale, need to be programme managed. A robust governance and accountability framework must be in place to realise the benefits of such as a solution, and IT infrastructure is paramount.

Social implications – Organisational development, collaborative as well as distributed leadership, and managing a change in culture towards health and care information is critical in order to create a supportive environment that fosters learning across organisational boundaries.

Originality/value – This paper draws on the recent experience of achieving large-scale data integration across the boundaries of health and social care, to help plan and commission services more effectively. This rich, multi-agency intelligence has already begun to change the way in which the system considers service planning, and learning from this county's approach may assist others considering similar initiatives.

Keywords Organizational development, Partnership working, Health and social care, Collaborative leadership, Data linkage, Information and intelligence

Paper type Case study

Introduction

Healthcare information and the digital technologies that allow the capture, storage and analysis of such data are critical to enabling evidence-based health and care decisions. The World Health Organisation supports member countries to implement robust health information systems in order to provide good-quality data to measure progress towards universal health coverage. In the USA, the US Agency for International Development has been funding the MEASURE Evaluation (Carolina Population Centre). Working with



developing nations this partnership between global, national and local agencies recognises that strong health systems are central to achieving better health outcomes, “and strong health information systems (HIS) are the backbone of strong health systems” (Carolina Population Center). In other parts of the world, in the realms of social services, organisations have acknowledged that implementation of successful information systems requires collaboration with the front-line workforce (Burton and van den Broek, 2008). However, such multi-agency, multi-professional innovations are rare and often beset with challenges.

In England the pace of change towards greater integration of health and social care services has accelerated. To support both the National Health Service (NHS) and Local Government transform services it is important to reconsider the healthcare information available at a local level. One of the most pervasive problems with delivering integrated healthcare systems is the barrier of multiple providers delivering different parts of a patient’s care. This, in turn, leads to fragmentation of information across different healthcare providers meaning that the patient’s “flow” through the system and the clinical benefits they realise are never captured in one place. It also makes identifying blockages in the flow extremely difficult. At the Nuffield Trust’s Urgent Care Summit in March 2015, Nigel Edwards, Chief Executive, commented that a major obstacle in handling current system pressures is the inability of health economies to understand “flow” (Blunt *et al.*, n.d.).

In 2009 a systematic literature review offered “ten key principles for successful health systems integration” (Suter *et al.*, 2009). Among these are a patient focus, geographic coverage, standardised care delivery through interprofessional teams, organisational culture and leadership, governance, and efficient information systems. The promise of an electronic healthcare record is often seen as a single solution. However, as AlJarullah and El-Masri (2012) note, the ability of national governments to successfully implement such electronic health records is poor. Whilst the benefits are many, the ability to integrate health records from a number of sources continues to be a significant problem. A more localised, semi-centralised approach may be a more manageable and deliverable option.

So whilst integrated care models are both a national priority and a local clinical necessity, integrated data systems that can both inform and support such models are notoriously difficult to develop and implement. In this paper we describe an approach taken across one county in the UK to bring together disparate sources of data and intelligence in order to support the development of more integrated health and social care systems. In its efforts to do so, the health and care community has begun to develop collaborative leadership and system-wide working. Leaders have begun to embed integrated information and intelligence at the core of the local transformation agenda towards a more integrated health and care economy. What has started as a county-wide approach covering a population of around one million people is broadening out regionally and, in future, may be adopted more widely. This is very much in line with the experience and development of information systems in other parts of the world (Aanestad and Jensen, 2011; Waterson, 2014).

This paper describes the development of a local integrated health and social care information system and its role in driving transformation at an English county level. It discusses the policy context nationally, the origins and implementation of the initiative, challenges and learning – “potholes along the road” and examples of new work undertaken. Our aim is to share the experience of a locality striving towards a vision of integrated information that is used to underpin an integrated future of health

and social care delivery. Some of the key learning we experienced includes how organisational development was equally important as the implementation of innovative new software; how managing change from grass roots through to strategic leaders was vital to success, and testimony that the whole is greater than the sum of its parts. The lead author was operational lead for this initiative, responsible for coordinating the virtual information and intelligence community. The second author was Director of Public Health in Derby and Visiting Professor at the University of Derby at the time of implementation, and offered strategic input and direction. The third author was technical lead and responsible for project directorship and day-to-day management throughout implementation.

Context and background of innovation

Since 2011 reform of England's Health and Care System has placed an emphasis on integration of care. The complexity of needs, particularly those living longer with multiple conditions, was increasingly being recognised at a national level at the time of early consideration of this project. During the government Spending Review of August 2013 a new fund was established, "to deliver better outcomes and greater efficiencies through more integrated services for older and disabled people" (HM Treasury and The Rt Hon George Osborne MP, 2013). The objective of this Better Care Fund (BCF) was to enable local health and care systems to do things differently. To respond to the increasing needs of the public at a personalised level by ensuring seamless delivery of health and care services. The enabler for this would be pooled budget arrangements between the NHS and local government, catalysing closer working arrangements in local areas "based on a plan agreed between the NHS and local authorities" (Downs and McCarthy, 2013). Operating in parallel to this was the Year of Care Partnerships (NHS England, 2015a), an NHS-based organisation driving improvement in the care of those with multiple, long-term conditions through ensuring that individuals were directly involved in their care planning.

In 2014 the NHS *Five Year Forward View* was published by NHS England setting the direction for a "better future" for the English NHS and those who are treated and cared for by it (NHS England, 2014). This necessitates a strengthening of partnership arrangements between the NHS and local communities, local authorities and employers. However, the divide between the disciplines of social care and the medical profession both geographically and organisationally, plus in its infancy a lack of clarity of purpose for integration and of each other's roles (Maslin-Prothero and Bennion, 2010), could make this challenging.

Derby City and Derbyshire County areas are situated centrally in England, in the East Midlands region. Derbyshire is rural in nature though interspersed with market towns and villages, of which Chesterfield is the largest town with a population of 104,288 (Office for National Statistics, 2015). The county as a whole has a population of 779,804 residents. To the north of Derbyshire is the Peak District National Park, the first established national park in England and Wales. In the south of the county is Derby City with a population of 252,463. The city has an industrial heritage and is internationally renowned for transport manufacturing, being home to Rolls-Royce, Bombardier and Toyota Manufacturing UK. As an urban, multicultural conurbation it is significantly more deprived than the Derbyshire county area and as such health, care and wider outcomes for residents are in some cases at polar opposites of the spectrum. Statistics for both life expectancy and healthy life expectancy at birth in Derby are significantly lower than average in England for both men and women, while in

Derbyshire they are comparable to the national average. At age 65, life expectancy for men and women in Derbyshire is significantly worse than average. Inequalities vary, including in use of health and care services by different population groups at different times of the year.

The Derbyshire Digital House of Care (DDHC) initiative has its origins in a workshop that took place at Royal Derby Hospital in November 2012. The aim of the workshop was to examine demand-side factors in Accident and Emergency (A&E) care. From its inception, it sought to bring together clinical and managerial leaders across the health and care system. The questions addressed in the initial workshop were “who uses emergency services, in particular who goes to A&E, when, where do they come from and where do they go to?”. The workshop generated sufficient interest for partners across Derbyshire to commission a project to test the concept of integrating health and social care data. The aim was to help respond to winter pressures across the system, particularly in relation to services needed by frail older people. Underpinning this, the chief executives (CE) of 12 participating organisations across Derbyshire sought to create a better understanding of how patients and service users flowed through their respective systems. With increasing financial constraint, there was a shared understanding that the “Derbyshire pound” could only be spent once and that the impact of parts of the system on each other in terms of increased pressure and even duplication of care should be eliminated wherever possible.

To explore this inequity in service use an exploratory pilot project emerged from the 2012 workshop. The objective was to derive insights for application during the winter of 2013/2014. At that time, Purchasing Index (PI) Ltd were the only supplier of a “software as a service” solution – Care and Health – that met the CEs ambition of a local integrated evidence base. PI had proven experience of working with a small number of other English health and care economies but the breadth of participation in Derbyshire was the largest undertaken at that time, as was the prevailing goal to develop a core knowledge and intelligence system that would support the fundamental redesign of health and social care across Derbyshire. In the event, the scale of change being experienced in the wider health and care system and the numerous practical and legal obstacles to be overcome resulted in this period essentially being one of laying the foundations of what was to become a genuinely innovative information sharing partnership. The timeline of key processes and activities during the pilot demonstrates some of these complexities (Figure 1).

The evaluation report from the Derbyshire integrated information initiative’s early adopting phase set out the context: “The system needs to work together to understand how collectively it is using its resources, and where demand is being felt in the system”. It described the benefits sought by the initiative:

- data linked across the whole health and social care system;
- understanding of need for services (conditions, prevalence, geographic and demographic distribution);
- understanding of demand (geographic, demographic, where services are received);
- better understanding of provision (volume and type of activity over time);
- outcomes (impact of interventions on level service use); and
- flow (interconnections between services and how they are accessed).

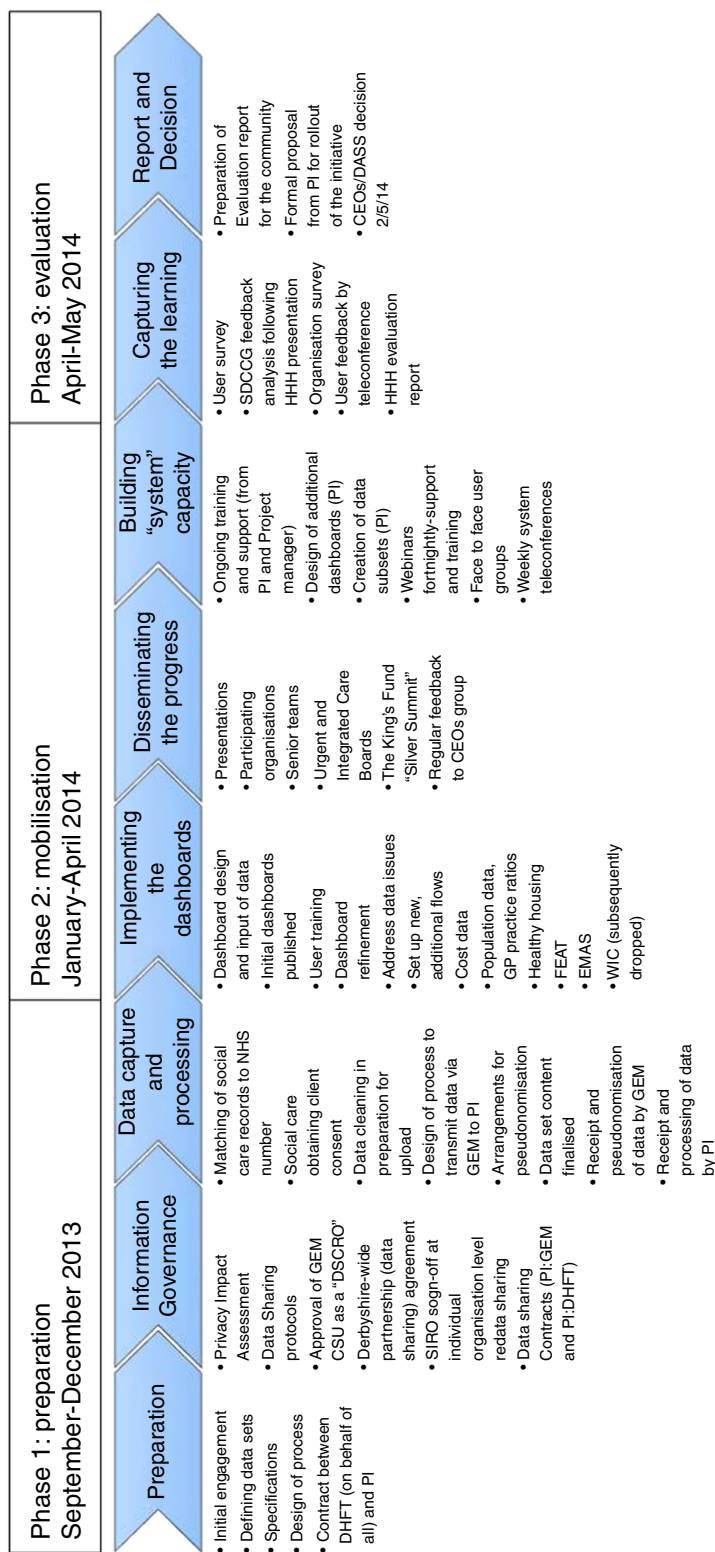


Figure 1. Timeline of the pilot

The journey from concept to eventual data integration encountered a series of challenges which varied widely, were often related to the unprecedented nature of the endeavour and many of which threatened to overwhelm the project altogether. With persistence and, by then, high levels of expectation for the end result, these were addressed, albeit at the cost of an extended timeframe.

In May 2014 as implementation of the BCF was imminent, findings were emerging from the National Year of Care Programme and actionable insights were beginning to emerge from the use of the Care and Health tool. NHS chief executives and their organisations now had access to eight integrated data sets across the county-wide health and social care economy. These covered two acute trusts, one mental healthcare trust, one community trust, two local authorities, ambulance and 111/out-of-hours data, with data covering the period from September 2011 to February 2014. A cadre of 20 individuals distributed through the organisations were trained in the use of the tool. System level working was underway, supported through face-to-face user groups, webinars, telephone conferences and presentations to whole system groups (Urgent Care Boards and Integrated Care Boards). In summary, the transition from project to “business as usual” was underway.

The DDHC

The NHS, local authority and social enterprise providers of health and care services capture an array of data items at the patient/service user level within a variety of clinical and information management systems. In order to realise the opportunities of an integrated system, these data needed to be linked at record level and then provided back to the Derbyshire Health Community as an integrated data set to allow analysis across providers. For the NHS the unique identifier is the NHS number, a unique identifier that every infant is assigned at birth and that remains with them throughout their life. Within the realms of social care this has historically been an elusive item but significant improvements have been made in the capture of this field in recent years.

Clearly such linkage raises issues of confidentiality and governance. Information governance leads across health and social services worked together to develop a robust and legally compliant framework for sharing the data in aggregated and pseudonymised form. The first task was to identify a secure data flow pathway and gain agreement from the data owners (the healthcare providers and Councils), the data processors (NHS Arden and Greater East Midlands Commissioning Support Unit (A&GEMCSU)) and the supplier of the system (PI Ltd). A&GEMCSU was tasked with the extraction and processing of healthcare information. Its role was to pseudonymise the data it received before onward transmission to PI. A&GEMCSU holds the pseudonymisation key which remains confidential to them. On receipt, PI linked the data, using the pseudonymised NHS number to match records for the same individuals across the various organisations (Figure 2).

In its infancy, most of this work was undertaken through the good will of all organisations involved. However, as this project became more embedded, it became essential that data flows were streamlined into structured processes that would allow uploads to occur consistently and systematically. In May 2014, a more formal arrangement between all the organisations involved was put in place. In support of this, contractual agreements were signed between Derby Teaching Hospitals NHS Foundation Trust on behalf of the Derbyshire Health and Social Care Community and A&GEM as the data processor, and between A&GEM and PI in respect of the onward transmission of pseudonymised data. A Data Management Service Level

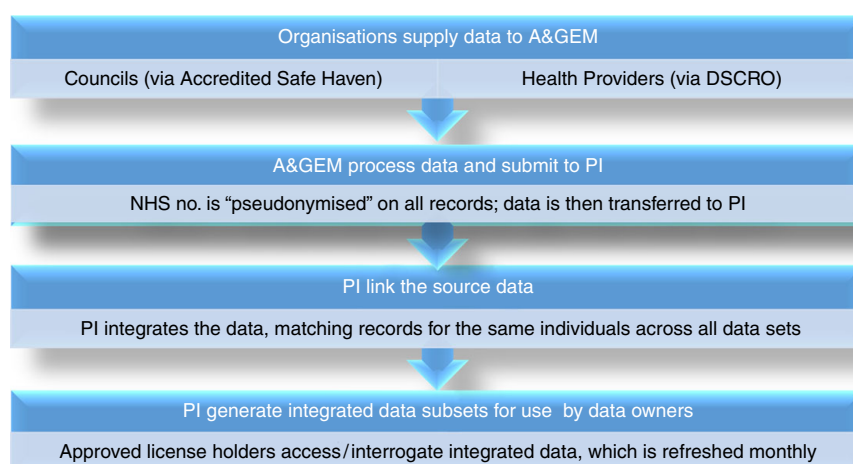


Figure 2.
Summary of
data flow

Agreement (SLA) followed, detailing data specifications, means and format of extraction, IG and security requirements, timing of delivery of data, change control, escalation routes to address outstanding issues, and the ongoing monitoring of the SLA. Beneath the SLA sat technical “schemas” for each data set. The schema illustrates the fields required for extraction and linkage, what format they should be in, a brief description and examples of where it is used for the benefit of the DSCRO technical delivery team.

Once the data were pseudonymised and transmitted by A&GEM, PI were able to integrate this using the unique identifier and provide the “big” data set back to the organisations on a monthly basis via licences to the Care and Health software. Once in the dashboard, organisational analysts and information leads were able to fully manipulate the product to produce bespoke higher-level dashboards derived from the underlying data.

The next step of the process was to consider at what geography to best analyse patient flows through the system. Derbyshire has two large acute providers, one in the north of the County and one in the south. Therefore, two virtual “Hubs” of analytical resource were created that aligned to these north and south Units of Planning.

How it is being used

The pilot phase of this programme of work, described above, demonstrated that the concept of data integration worked. The Derbyshire Health and Social Care Community overcame organisational boundaries, such as the divide between the disciplines of social care and the medical profession, and embraced integrated data. This in turn provided unique insights into population need, service redesign and pathway outcomes, resulting in opportunities for the evaluation and commissioning of services in a joined-up way. These enablers are fundamental to the strategic ambition of Derbyshire’s Health and Well-being Boards; to support people to have the best quality of life within the constraints of their personal circumstances.

The Derbyshire Health and Social Care Community’s ability to understand flow across the system at a granular level is unique. A holistic view of how patients and service users move through the health and care system is now available informing how “joined-up” services really are, as is the opportunity to explore treatment and care received by cohorts of the population before and after key events. It is now possible to

determine whether services designed to reduce use of more intensive provision did in fact reduce demand. Pathways by geography, time, diagnosis and other key demographic factors can now be explored, and integrated data can now be “sliced and diced” to understand anomalies and connections between services.

One such example of how these insights have been applied is in relation to the topic of “falls”. Falls in the older population and those living with frailty continue to represent a significant challenge to both commissioners and providers of health and care services. They are a significant determinant of the morbidity and mortality of this population and as such, falls prevention is high on each organisation’s agenda. Early identification of those at risk of falling and setting up fracture prevention services for older people have been found to reduce hospital admissions and the need for social care, such as admissions to care homes. It is generally regarded that the health and care needs of an ageing, frail population will be complex. However, unless they are being explored on a case by case basis it is difficult to visualise the breadth of complexity for that population group as a whole. The DDHC offered a solution.

Commissioners were keen to determine whether there were opportunities in other service settings to offer preventative advice to those who were at greater likelihood of later experiencing a fall. Previous local analysis had revealed that the Royal Derby Hospital received one-third more blue light attendances for falls than the England average and one-quarter more against a comparator group of acute hospital Trusts. At that time, there was limited access and capability to share and visualise data in a meaningful way from other sources to explore the reasons for this. However, with the DDHC programme it was possible to identify a costly cohort of fallers who had been in receipt of A&E care, and follow their pathways of care back through time.

Exploration of the emergency service data revealed variations in pick-up time and the decision to convey or not to convey the patient. It was discovered that this variation was associated with proximity to the A&E Department at Royal Derby Hospital. On arrival at hospital in the cases of emergency admission to a bed, it became apparent that many cases were not always being admitted for clinical reasons necessitating a period in hospital, rather primary diagnoses of urinary tract infection, senility and having “Tendency to Fall”. The evidence base suggests that in these situations, care can be better offered in a more comfortable and less costly community setting. Outpatient appointments account for the largest volume of health service contacts and in this group of fallers it is no different. However, of note was that the costliest pathway for these patients was dominated by a combination of three outpatient appointments followed by the emergency admission via A&E. Many of this cohort were being seen in an ophthalmology setting prior to their fall, and were already well known to trauma and orthopaedics and therapy specialities. Evidently this group known to have fallen were already well known to professionals prior to the event.

This prompted a clinical audit of Royal Derby Hospital A&E falls admissions in those aged over 65 years who were recent and recurrent outpatient attendees. The aim was to determine the scope for using existing outpatient contacts of frail elderly patients to reduce the rate of their subsequent falls-related admissions. The audit initially collected a group of 1,144 patients who had a total of nearly 8,000 outpatient attendances in the year preceding their admission. From this group, a random sample of 100 patients were selected for audit. The results of the audit gave further insight into the health and social circumstances of this group, including home living situations (type of residence and support, including cohabitants), prescribed medications, and the

falls incident itself further broken down by environment, activity and mechanism as originally documented in the A&E clinical notes and/or discharge summary.

The DDHC and resulting audit has offered professionals, including front-line clinicians as well as commissioners, an enhanced understanding of this small in volume but high in cost cohort of patients. A recommendation from the findings of this work was that a pilot referrals programme be run in one of the identified high-attendance clinic settings. Ophthalmology clinic was the obvious choice. The referral programme could comprise of a brief but evidence-based screen for all clinic patients using easily identified falls risk factors. Positively screened patients are then invited to perform one of the recommended NICE fall risk tests. Those deemed at high risk following on from this test are then referred into a separate service, including a comprehensive multifactorial falls clinic or another evidence-based intervention such as a community exercise programme. This approach would require minimal extra resource but has the potential benefit of identifying previously neglected falls risk patients. At the East Midlands regional level, Public Health England has agreed to pursue this in partnership with Royal Derby Hospital.

Other specific falls care pathway services highlighted for attention included the Frail Elderly Assessment Team (FEAT), based on a global evidence base of Comprehensive Geriatric Assessment (CGA), and Derby City Council's "Healthy Housing Hub" (HHH). The FEAT emerged as a commissioned, evidence-based intervention from the local learning about the management of frail elderly patients by the existing Medical Assessment Unit at the Royal Derby Hospital. Evidence suggests that a CGA model of care would offer significant benefit to patients both in terms of increased independence and reduced mortality, as well as to functional decline or death at six months. Similarly, Derby's HHH was established based on the evidence base for poor quality housing and fuel poverty, both of which are widely considered to be determinants of poor outcomes in health and wellbeing. Established in 2012, the aim of the HHH was to mitigate the effects of housing on health through implementation of low-cost preventative solutions in the home.

Though both services were commissioned on the assumption that they would support independent living; reduce admission and/or facilitate hospital discharge; reduce longer-term demand on health, social care and emergency services, there is limited evidence from local initiatives that these outcomes can in fact be realised. Whilst qualitative, case study based evidence captured locally would suggest that both services offer significant health and wellbeing gains at the individual level, objective evidence at the population level would offer a far more robust means by which commissioners can consider investment or disinvestment in the services. Using the DDHC and linking both client cohorts to their wider health and care records, both services are currently being objectively evaluated by means of a retrospective case and control study. The intention is to publish the results of both studies separately and enhance the local evidence base.

Key challenges and lessons learned

Although the technical aspects of this programme have focussed on the IT issues, it quickly became apparent that, in order to fully benefit from the new data integration, a focus on organisational development would be crucial. A cultural shift in behaviours towards data, information and intelligence functions to support planning and commissioning decisions has taken place. To support this transition, organisations were actively encouraged to generate their own insights rather than follow a central

directive. This was an exercise in “distributed leadership”. That is, cultivating an environment by which individuals learn by doing and then share their knowledge for the benefit of not only their own organisational objectives, but also of the system as a whole.

However as the project picked up speed it quickly became apparent that subject matter specialists (IT, IG, business analysts) were frequently unaware of their counterparts in other organisations. It was therefore important to create opportunities for them to build communities of interest, share their projects and build shared knowledge. In doing so, it was soon recognised that the needs of one’s own organisation almost always take primacy above “the system”. Amplified, this on occasion meant that other agendas risked undermining the wider project.

Sustainability of the knowledge base vested in the users of the tool was a challenge during a period of reorganisation/system change. Since inception, several key specialists had moved out of the Derbyshire system taking with them experience in their organisation and field. To mitigate this, new users of the tool were quickly identified and welcomed into the wider community of users, facilitated by monthly teleconferences, quarterly reviews and training opportunities.

The fact that individual organisations understand their own data, but not each other’s, was reinforced. It was quickly established that there is a learning curve covering what the data actually means and a “Data Dictionary” session, whilst perhaps sounding uneventful, actually proved surprisingly insightful. It allowed users to talk to the rest of the community about their data sets, including what specific fields meant and where it was appropriate to include them. A willingness to learn by doing, and creating a supportive learning environment against a backdrop of time-pressured deadlines for delivery was paramount. A key finding from this work is that practitioners need to be given time to interrogate the integrated data source and derive actionable insights, supported by knowledgeable practitioners: be they front-line clinicians, commissioners, or service providers.

Historically, professionals have been reasonably successful in understanding what is going on within individual organisations, and have nurtured information experts who are well versed in the data captured by their organisations about their service users. What has been striking about this process is that the integrated system has required a shift in thinking from more traditional means of considering disparate components of the healthcare system, to viewing the system as a whole. Practically, this has meant that social care information officers are now getting to grips with hospital data, while hospital information analysts are interpreting primary out-of-hours service provision information. This very much supports the view that in order to successfully discharge patients from an acute bed, a broad range of support services need to be understood and in place if readmissions are to be avoided. Equally we now have evidence of areas of primary and secondary prevention and intervention that are reducing demand and impact on secondary care services.

Summary and conclusion

Over and above the considerable benefits we have derived using the tool, we have united information and intelligence specialists across the system. This is new and proof that the whole is indeed greater than the sum of its parts. It has improved understanding between health and social care about how services are delivered and has offered the foundations for a new model of intelligence delivery for Derbyshire. In recent years there has been an increased drive towards the integration of health and social care. The Spending Review and Autumn Statement 2015 sets out a plan that

health and social care are integrated by 2020. There is also a driver towards “place-based” systems of care and commissioning. This requires planning and provision “by place” for populations rather than individual organisations. It is anticipated that the new models of delivery will redefine the boundary between commissioning and provision and that commissioning will become a primarily strategic function. The progression of devolution deals and new models of care will also require a system, rather than an organisational approach. Whilst individual organisations will continue to require intelligence to support their own planning, provision and business management, the requirement for cross-system intelligence is increasingly needed to support these changes. This fundamentally requires improved relationships across organisations to support partnership working.

Top down, integrated health IT systems very seldom work. This is borne out by our local experience. Rather than waiting for a national integrated health record to be delivered the Derbyshire Health and Care System has developed a working model that integrates data from a range of provider organisations. These data are then used to follow patients through the system and get a real understanding of “flow”. By bringing together clinicians, commissioners and information specialists we have been able to identify specific problems within integrated care pathways and to test out solutions. The integrated data have enabled detailed analysis, across organisations and sectors, which in turn has supported clinical audits and changes to the care pathways. As the Derbyshire Health and Social Care Community develop their sustainability and transformational plans (NHS England, 2015b) the integrated data system will be used to support all aspects of the work and will help to develop a model that truly works for the people of the county.

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