Integrated Digital Care Records
- Enabling information sharing

Contents

"The creation and adoption of integrated digital care records is not an end in itself. It is the backbone upon which increased transparency and participation in our health and care system depends."

Tim Kelsey, 'The Integrated Digital Care Fund: Achieving Integrated Health and Care Records'

Introduction

Computers used to be seen as tools for complex calculation, data processing, or replacement typewriters. However, as technology has developed, so has its uses, and in a modern 'digital' healthcare system, technology is no longer just seen as a way to support change, but as an enabler, directly shaping and driving transformation.

The potential for technology to drive transformation is clearly articulated in the government's ambitions for better use of digital technologies. Within health and social care, providers are expected to transform clinical effectiveness and outcomes, reduce the administrative burden on frontline staff, and enable the integration of care around the person being treated.[1]

Integrated Digital Care Records (IDCRs) and Digital Care Records (DCRs) are seen as a key part of 'better use of digital technologies', with the vision for fully integrated digital care records across all care settings by 2018 at the heart of ambitions for a paperless NHS.[2]

However, when an IDCR is introduced, its impact goes beyond its direct operational capabilities (supporting the flow of high quality, up to date, patient level information between healthcare professionals), as "Having access to the right information at the right time enables excellence." and is "...key to the introduction of new workflows and process improvements...".[3]

In looking at how IDCRs have been developed and implemented in different places, we have seen how this wider impact relates to information sharing. Exploring how multi-agency collaboration and co-production approaches during the design of an IDCR can help build the relationships, trust, shared vision and common language between partners so essential for successful information sharing. We have also been able to consider how the tangible nature of an IDCR system (its potential to show information sharing 'in action', and demonstrate benefits), and the involvement of stakeholders in its ongoing development, can help to change attitudes towards information sharing, and drive culture change.

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[1] Foreword, Sir David Nicholson, 'Safer Hospitals Safer Wards: Achieving an integrated digital care record', July 2013. https://www.england.nhs.uk/wp-content/uploads/2013/07/safer-hosp-safer-wards.pdf

[2] Department of Health press release, 'Jeremy Hunt-challenges NHS to go paperless by 2018', 16 January 2013. https://www.gov.uk/government/news/jeremy-hunt-challenges-nhs-to-go-paperless-by-2018

[3] Introduction, Tim Kelsey, 'the Integrated Digital Care Fund: Achieving Integrated Health and Care Records', May 2014. https://www.england.nhs.uk/wp-content/uploads/2014/05/idcr.pdf

Case study scope

This case study looks at the role of Integrated Digital Care Records (IDCRs) to support information sharing as part of a wider programme of health and social care integration.

Drawing on a range of interviews and document reviews from four locations - Bradford and Airedale; Bristol, North Somerset and South Gloucestershire (BNSSG); Hillingdon (North West London); and Leeds – the Centre has compared different approaches to the implementation of IDCRs, identifying key barriers and benefits to implementing an IDCR. Common themes and lessons learnt have also been highlighted, sharing local place learning on IDCR implementation and adoption, and to make recommendations for future activity.

This case study also explores how multi-agency collaboration and co-production approaches, used during the design of an IDCR, can help build the relationships, trust, shared vision and common language between partners - which are essential for successful information sharing.

The key themes which have come out of our analysis (below), have been used to structure this case study, and following an overview of the IDCR approach in each area, benefits and challenges, are explored in turn:

▶ Vision

▶ Leadership

▶ Partnership working and relationships

▶ Communication

▶ Engagement with partners, providers and patients

▶ Initiating change

▶ Training

▶ Starting small

Approaches to IDCRs in local places

There are a lot of different terms used to describe digital or electronic patient records in the healthcare sector. In this case study we generally refer to Integrated Digital Care Records (IDCRs) in line with the descriptions used by the local place. However, it is worth noting that whilst all of the local places are part of a wider Health and Social Care Integration programme, not all of the examples below currently include sharing of patient records between health and social care, focusing instead on bringing together data from within the different parts of the health sector.

Integrated Digital Care Record Programme for Bradford, Airedale, Wharfedale and Craven

The Integrated Digital Care Record (IDCR) for the Bradford and Airedale district integrates information from a number of local digital systems into a single, shared record. Through the use of a common software system (SystmOne[4]) and integration engines, authorised care providers with a legitimate relationship with a patient, can access all available information provided by each of the contributing partners.

Patient medical records are accessible by partner organisations across all care settings including A&E, community health, urgent care and out of hour's services. Information currently comes from 85 GP practices, Airedale Foundation NHS Trust, Bradford District Care NHS Foundation Trust, and Bradford Teaching Hospitals NHS Foundation Trust. Information will also be available from adult social care services, following migration onto SystmOne. In addition, Mental Health services in the district (who use RiO[5]) have also recently been connected to the pooled record.

Information that is shared through the record includes patient name, address, GP details and telephone number, diagnosis, medications, allergies, care referrals, clinic letters, discharge information and physical health reviews. Care providers can also see who else is involved in providing care to a patient and ensure that they work together in wrapping necessary requirements around the service user.

The pooled record supports work being done to avoid preventable hospital admissions, long term residential care and unnecessary dependence on the health and social care system. The district is also reviewing existing consent models and information sharing agreements, to ensure optimal use of sharing opportunities.

Safer Hospitals, Safer Wards Technology Fund provided the resources to accelerate the implementation of the IDCR. Through this bid Bradford was identified as a national accelerator/exemplar sites, and aims to make the district one of the first in England to join up the health and social care information of residents. Once social care 'go live' as part of the pooled record, Bradford hope to be one of (if not the first) care communities with access to a real-time, detailed care record with simultaneous 'read' and 'write' access across health and social care.

Connecting Care - Bristol, North Somerset and South Gloucestershire's (BNSSG) interoperability programme

Connecting Care is a National Exemplar site for clinical systems interoperability and has won two EHealth Insider (eHI) awards. The vision for the programme, developed in partnership with over 60 stakeholders, is to use technology and share information better to support the changes needed across the health & social care system.

The aim of the programme is to provide an integrated care record for people in Bristol, North Somerset

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[4] SystmOne is a centrally hosted clinical computer system developed by Horsforth-based TPP (The Phoenix Partnership).

[5] RiO is a single product platform developed by Servelec Healthcare (part of Servelec Group)

and South Gloucestershire (BNSSG). An approach designed to tackle reported concerns that a lack of access to shared, accurate information was a blocker to the provision of high quality care. The first stage of the programme focused on delivery of a shared 'view only' portal to share patient records for urgent and unscheduled care. As a result of successfully testing the concept during this pilot stage, the team delivered a business case to extend the breadth and depth of Connecting Care during the current second stage.

Following a formal procurement process, the Connecting Care delivery team started working with Orion Health in March 2013 and Connecting Care went live in December 2013. There are 17 partners[6] involved with the programme, spanning a range of different organisations, including local authorities, clinical commissioning groups, hospital trusts, GP practices, community health services, mental health partnerships, ambulance service, and a regional academic health science network.

The decision to use a portal model (Orion Health Cross Community Care Record[7]) to create a shared care record was reached following evaluation of a range of options. This approach was felt to be the best option for the region given the disparate systems and range of organisations involved. It also reflected the desire locally for Connecting Care to be driven by a partnership of equals, with no one organisation owning the pooled data, or imposing its 'own' system on the others in order to be able to share information.

Connecting Care brings together information from 11 previously separate information systems, enabling authorised professionals to log in and see a comprehensive summary of an individual's health and social care data in a single electronic view. Information contained in Connecting Care includes patients' medications, diagnoses, immunisations, allergies, test results, hospital attendances and Social Care and Community referrals and appointments.

A role-based access approach has been used for the Connecting Care programme, with access to appropriate levels of information in each area of the system. Building on this approach, BSSNG are adding new requirements to meet the needs of the current project; for instance, further consideration of appropriate levels of information in each area of the system, and how this information is accessed by different types of social workers. New projects – such as the Children's Safeguarding currently being worked on – have thrown up different challenges, such as the need to enable users to monitor risks as well as manage care, requiring different security profiles and more depth of information against particular elements, such as legal and family relationships of children in need.

Recognising that funding for the programme would be significantly limited until the case for change was proven, a two-stage approach was used. The pilot stage (starting in March 2013) involved a limited system roll-out to 500 health and social care professionals involved in unplanned and urgent care needs. Careful evaluation of this phase (in early 2014) was used to build a convincing proof of concept in order to bring others on board. Stage 2 (launched in September 2014) involves scaling the programme up to reach an additional 2000 users per year across more disciplines, including GP practices, specialist community care services, social care and other hospital settings. Ultimately this second stage will extend the breadth & depth of information sharing with an additional 10,000 users of Connecting Care.

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[6] Partners currently working together are: Bristol Clinical Commissioning Group (CCG); North Somerset Clinical Commissioning Group (CCG); South Gloucestershire Clinical Commissioning Group (CCG); North Bristol NHS Trust (NBT); University Hospitals Bristol NHS Foundation Trust (UHB); Weston Area Health Trust; Bristol City Council; North Somerset Council; South Gloucestershire Council; Bristol Community Health (BCH); North Somerset; Community Partnership (NSCP); South Gloucestershire Community Health Services (Sirona); Brisdoc (and OneCare); NHS England (Area team) for BNSSG (Bristol, North Somerset and South Gloucestershire); GP practices in Bristol, North Somerset and South Gloucestershire; Avon and Wiltshire Mental Health Partnership NHS Trust (AWP); The West of England Academic Health Science Network (WEAHSN); South Western Ambulance Service; NHS Foundation Trust (SWAST); NHS South, Central and West Commissioning Support Unit (SCWCSU).

[7] Orion Health Cross Community Care Record (CCCR) provides care teams from across different settings with a single view of patient information, and can be launched from within a user's "primary" system.

Hillingdon (North West London)

Within North West London, Hillingdon CCG and the Hillingdon Hospitals NHS Foundation Trust hold a leading position on interoperability and shared care records. This work has included the development of a Medical Interoperability Gateway (MIG) - a tool which supports sharing of the Hillingdon Local Care Record between primary care, unscheduled care settings, and hospitals.

The development of Hillingdon's Medical Interoperability Gateway, and the shared access to records resulting from it, was driven by the desire to support a number of wider transformation programmes, in particular a major transformation programme across North West London (NWL) – known as Shaping a healthier future – which included a redesign of emergency care services and a focus on 'out of hospital' care; plus the roll-out of an electronic Summary Care Record (in line with national objectives).

The MIG, provided by Healthcare Gateway[8], enables access to a Shared Care Record by a number of different service providers, including:

- ▶ Care UK (providers of the local Out of Hours and NHS 111 services)

- ▶ Greenbrook Healthcare and Ealing Integrated Care Organisation (Urgent Care Centre based in Hillingdon Hospital)

- ▶ NHS Hillingdon Hospitals Foundation Trust (Acute Medical Unit, A&E, Pharmacy, Minor Injuries and Paediatrics)

The implementation of the Medical Interoperability Gateway (MIG) system has been led and funded by Hillingdon CCG. Phased across the different services, and partners involved implementation of the MIG. This phased roll out, and the order in which the MIG went live in different services, was mainly due to different technical infrastructures, and the differing speeds at which services were able to implement the MIG.

The partnership project group looked at both the development of the MIG itself and the organisational structures that support the use of the MIG. Partners also developed a joint communications plan, and shared materials used to engage frontline practitioners.

An Information Sharing Agreement (ISA) was developed to set out the arrangements for patient records to be accessible to clinicians in providing NHS 111 and OOH services, the Hospital and the Urgent Care Centre service.

Around 90% of GP practices in Hillingdon have signed up to the data sharing arrangement following a successful programme of engagement and support by the CCG. Engagement of hospital staff with the MIG was managed and delivered by the Hospital trust, with support from the CCG, who shared the documentation developed for engaging people in the Primary Care sector with the hospital trust.

The presence of the MIG, and the sharing it facilitates, is generating demand for further sharing which goes beyond the original scope of the system. As a result, work is underway locally, and at a NWL-wide level, to look at best ways of doing this, by developing new systems and /or using existing systems.

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[8] Healthcare Gateway's MIG is a national interoperability solution delivered locally, providing secure access to whole-life health records in order to deliver safer, more efficient care.

Leeds Care Record

The technology used to build Leeds Care Record has been developed from the well-established Leeds Teaching Hospital Trust's PPM+ system, a trust-wide electronic patient record. Devised as a response to a health and wellbeing priority for the city to support integrated health and social care, the Trust's strong in house offering was a natural and trusted place to develop the secure system for the city.

A web based solution; the Leeds Care Record enables care professionals and practitioners to view real time data across care providers and between different systems. It is a collaboration across:

▶ Primary care

▶ Secondary care

▶ Adult and children's social care

▶ Mental health services

▶ Part of the integrated health and social care programme in Leeds.

The Leeds Care Record does not replace existing systems or add additional administrative burden on care professionals and practitioners; instead it adds value and insight to processes which are already in place.

To enable the Leeds Care Record to realise its full potential, health and social care commissioners and providers collaborated to develop a standard suite of information governance documentation that all participating organisations signed up to. This collaborative approach provided both a gateway for sharing and ensured a shared understanding of the data that needed to be shared and how that would work.

All 107 GP Practices in Leeds (approx. 817,000 patients) are currently live with Leeds Care Record. It has also been rolled out across the Leeds Teaching Hospital Trust, Leeds York Partnership NHS Foundation Trust and all thirteen health and social care neighbourhood teams.

Leeds Care Record is held on a secure computer system and includes key health and social care information about a patient. It is currently a read-only system. The information on each clinical system that can be accessed is dependent on the practitioners' health care role and can only be changed at the source by those authorised to do so. Information shared through the Leeds Care Record includes:

▶ Address and telephone number

▶ Diagnosis list

▶ Medications

▶ Allergies

▶ Test results

▶ Referrals, clinic letters and discharge information

This information allows care professionals directly involved in a patient's care to make more informed decisions, drive efficiency and improve outcomes regardless of where they are based.

Both care professionals and patients were at the centre of all discussions and the decisions made, with a patient advisory group established to ensure the patient's voice was evident throughout the development of the Leeds Care Record.

The latest development for Leeds Care Record provides GPs with a single view of their patients that have been admitted to wards across Leeds Teaching

Hospital Trust sites called 'virtual ward'. It assists care professionals in understanding what is happening to their patients whilst they are in hospital.[9]

The long term goal is for a fully integrated care record which spans all patient journeys. Within the near future it will be available to all neighbourhood teams and will be piloted with six teams across Adult and Children's Social Care and Leeds Community Healthcare. These pilots will allow a number of social workers to access Leeds Care Record. Further plans to comprise information from these organisations are to be included later this year, with the opinions of service users at the heart.

Initial conversations have taken place with other organisations across these journeys for example; care homes, Yorkshire Ambulance Service and pharmacies. Organisations still use their system of choice; Leeds Care Record simply pulls agreed datasets from those systems into one place to enhance integrated care.

Challenges and Benefits

Challenges

Looking across all four local places, the following common challenges have been identified:

▶ **Differing interpretation of legislation (governing data sharing) -** The issue with legislation is that the interpretation can vary depending on who you are speaking to (both between individuals in the same organisation, and between different organisations). This was an area in which BNSSG felt that relationships between partners were crucial. Partners believed that by building trust they could develop a combined interpretation of legislation. Getting the right guidance has also proved to be a challenge, with a number of different source documents and agencies to draw from. Links with the ICO and HSCIC provided invaluable support and guidance on legislation to the partners in BNSSG for the Connecting Care project.

▶ **Data quality -** Each area identified a number of operational barriers to sharing information during the development of programmes. Many experienced difficult conversations early on about how information should be shared appropriately between partners. There were also concerns about data quality within systems, so time has been taken to address any data quality issues before the inclusion of a service areas' information.

▶ **Consent -** Consent and who takes responsibility for the ownership of data has provided a significant challenge for all local areas. Joined up systems across primary and secondary health care, with GP patient records, is key to the integration of this information.

In Bradford and Airedale consent is gained each time a service interacts with a patient, resulting in a complex 'share in / share out' arrangement. Information is only shared if explicit consent to share an individual's information has been secured from the patient at both the point that information is written on to the system and also at the time when it is to be viewed.

If a GP has not recorded that consent has been given by a patient when they share the information with A&E, the A&E staff are unable to access it. This is still the case if the patient provides consent directly to A&E, as the GP is seen to 'own' the information. As such the region is reviewing the local consent model with all Health and Social Care Agencies with an aspiration to engage with general public about introducing an implied consent model controlled through Smartcards and role based access.

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[9] More details on 'virtual wards' in Leeds can be found in the Leeds Care Record case study on www.informationsharing.org.uk

Benefits

The benefits for an integrated digital care record vary depending on the interpretations and priorities of a local place. Benefits identified within these case studies include:

▶ **More efficient use of resources –** Some of the benefits seen for patients as a result of the Leeds Care Record include more efficient use of healthcare services, fewer unnecessary clinical tests, less paperwork, and more time to spend on clinical care.

"I have been using the Leeds Care Record for the past couple of months now and have found it an invaluable aid to my clinical practice. It gives me a window into the hospital – I can see when my patients have appointments, which of my patients are in hospital and allows me to view letters and results that may have not arrived at the practice. It has saves a considerable amount of practice admin time – our admin staff no longer have to spend hours on hold trying to find out when the patient's next outpatient appointment is. It is a really useful and easy to use system that bridges a major healthcare gap in the city."

Dr Adrian Ress, Partner Yeadon Tarn Medical Practice

Similarly, during the pilot stage of the BNSSG Connecting Care programme, partners realised that sharing information electronically could save not just time but money – removing duplication and reducing administrative costs of maintaining separate records. Examples of the possible savings which Connecting Care could realise, based on actual impacts identified in the evaluation of the pilot stage, include:

- **Admissions prevention –** The pilot illustrated that savings were possible. This could equate to annual savings of £1,036,288 from admissions (based on 10,000 people using information in Connecting Care (based on £1,436 cost for an unplanned admission – Dept. of Health reference cost 2012/13)

- **Time savings –** Annual savings of £155,278 of 'people time' as Connecting Care users spend less time calling other organisations for information (based on evidence from the pilot and on the calculation that if only one call per week saved using salary cost savings for a medium salary between NHS bands 7-8)

- **Reducing home visits –** Annual savings of £68,000 on stopping unnecessary home visits as a result of 10,000 people using information in Connecting Care (based on £60 average cost of a face to face assessment by a Community Nurse, Dept. of Health reference cost 2012/13, and savings realised assuming the same rate of stated home visits prevented during the pilot stage)

▶ **Reducing risks and improving care -** With regard to patient care, IDCRs have been demonstrated to reduce unnecessary delays in treatment, enable more accurate prescriptions, and provide better co-ordinated and safer care.

In Hillingdon, Hospital pharmacists in the Acute Medicine Unit, can use the MIG to access patient's medication data to conduct a general review of their medication when they are admitted, as well as looking at specific medication needs for the immediate issue. Out of hours doctors can also access the patient's records to check for allergies, existing medication etc. Access to patient's records for out of hours or Urgent Care Centre practitioners also supports a system of 'double assurance' which helps ensure patient safety. For example, whilst clinicians are trained to always ask patients about allergies, the ability to check patient records at the same time helps prevent problems.

▶ **Smoother transitions –** Practitioners recognise the benefits that shared access to one view of the patient/citizen care record brings, particularly for processes such as hospital discharge and in supporting integrated teams, for example, GPs, social workers and community staff working together in multi-disciplinary teams.

Social care access to the Leeds Care Record on a role based permission level, aims to ensure timely reactions to patient's emergency admission, enabling care packages to be halted during hospital stays, and re-started on discharge. This improves the co-ordination and hand-overs between services (and saves money across the system).

"The virtual ward development for the Leeds Care Record has really helped my practice prepare for our patients being discharged from hospital. With one quick simple view I can understand where patients that I'm directly involved in caring for are and what their likely needs will be when they return to the community."

Dr Chris Mills, GP from Rawdon Surgery

Hillingdon has also found that access to shared patient data is providing a quicker and smoother process for patients and staff as out of hours doctors can access medical history and request follow-up interventions from local GPs. The out of hours clinicians can also see if the patient's GP has noted any existing concerns they need to take account of in their assessment, or request a follow up from the GP. This makes the consultation quicker, more efficient and can help can help to provide patient's with more joined up care.

▶ **Driving / Increasing the appetite for sharing –**
In Hillingdon, the presence of the MIG, and the sharing it facilitates, is generating demand for further information sharing. This includes sharing of information with other parts of the healthcare sector (not currently included), the development of the system's capabilities, and a widening of range of teams with access to patient records via the MIG (to support their role in direct care). The existence of an IDCR as a driver of interest in / use of information sharing was also experienced in BNSSG, for example where they were proactively approached by a group of pharmacists who told the project team who else might need the system and asked for them to be given licenses.

The impact of developing a local IDCR can also go beyond the immediate health and social care economy, driving the potential, and appetite, for information sharing across the country – as demonstrated by the Ripple Programme.[10] Emerging from the learning and experience gained during the implementation of the Leeds Care Record, Ripple is building an open source integrated digital care record which enables other organisations and localities to develop a shared care record platform that is not system or vendor dependent. Funded by the NHS Tech fund and hosted by Leeds, the programme is focused on delivering six offers which can be used in their entirety or as individual components of integrated digital care record development. These six are: open requirements, open governance, open citizen, open viewer, open integration and open architecture - documents, toolkits, software, specifications and code which are available under an open source licence.

By taking a collaborative, innovative and open approach in the journey towards an Integrated Digital Care Record, Ripple aims to change health and social care for the better with an inclusive approach to learning, sharing outcomes and experience with a blend of open source technologies.

▶ **Supporting service redesign and continuous improvement –** The development and roll-out of the Leeds Care Record has helped facilitate an accompanying programme of service review and redesign. To support this there has been a focus on both continued compliance with requirements such as the 'fair processing' strand of the Data Protection Act and improving outcomes for patients. An example of this can be seen in the revision of the Fair Processing notice used by Adult Social Services to cover the integration of Social Care data into the Leeds Care Record. The notice was revised to incorporate all the new features (of the Leeds Care Record) and supported by complimentary changes to the Leeds City Council leaflet 'How we look after your information'. In addition to changes in written materials, changes were also made to the accompanying processes. For example, changes were made to ensure that the 'How we look after your information' leaflet is given to all new services users on their first visit by a social worker. Social workers also have to sign to confirm that they have given the service user the leaflet and explained the contents to them. New processes were also put in place at the Social Care Contact Centre to respond to individuals who want to opt out of information sharing or have refused to give consent. This has included the development of new scripts for Contact Centre staff specifically regarding consent and opting out of information sharing arrangements. Anyone telephoning the Contact Centre will also hear a recorded message regarding information sharing before being put through to a Customer Services Advisor.

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[10] For more information on Ripple, visit www.rippleosi.org or email ripple.osi@nhs.net.

A sample of benefits attributed to Connecting Care by local practitioners:

"Unable to obtain a **medication history or allergy status** from the patient… accurately confirmed through connecting care…" **Pharmacist, NBT**

"Information about the patient's diagnoses has helped our team **decide which type of therapy** to offer the patient" **UHB**

"Connecting care is **brilliant**… I use it to triangulate information from service users, to find out about other service involved so that I can contact them to **inform my assessments**." **Bristol Social Worker**

"On Monday I managed to obtain details for 22 patients on Connecting Care, I **saved a huge amount of time** as I didn't need to phone to GPs and wait for the faxes to arrive." **Acute Pharmacist**

"In cases where we are dealing with a person who is being supported by Rapid Response and the district nurses, Connecting Care comes in to its own. All the notes from visits are documented and it **can save at least 30-40 minutes on duty cases of this nature.**" **Social Worker**

"I now use Connecting Care on almost every case I deal with (approx. 25 cases per shift). It always makes a difference and adds value. **Every shift, acute admissions are avoided.**" **Doctor (out of hours)**

"Have been able to identify trends which have then resulted in swifter **(safeguarding) interventions**… one case where concerns would not have increased without Connecting Care…" **Social Worker Safeguarding team**

"Without Connecting Care today I couldn't have done my job." **Pharmacist**

"Connecting Care has been really helpful tonight. Could not do without it. Particularly in the case of an old lady I couldn't reach on the phone. Without Connecting Care this **would have resulted in a visit and probably her door being broken down.** Instead I was able to work out that all that all that should have been done, had been done." **Doctor (out of hours)**

The extra patient detail is useful when deciding to stop drugs such as anti-platelets and it **helps to identify risk factors.**" **Doctor**

"Massive difference in time spent accessing information. On average (I can) access the GP record within **30 seconds, compared with 15-20 minutes** taken via telephone or fax." **Critical Care Pharmacist Manager UHB**

"It has enabled us to commence discharge planning earlier in the patients stay to **help prevent delays later on**." **Discharge Nurse**

"3 cases identified on Connecting Care today that were already allocated to a health practitioner (BCH OT or IMCS OT) so **did not require referrals** to BCC OT." **Occupational Therapist Bristol City Council**

"Having access to accurate, timely, shared information is no longer a 'blocker' to providing high-quality, effective, efficient care…"

"I used Connecting Care to **find vital information for the diabetes nurses**. The information logged by them is a goldmine of information. We saved 20 minutes on the telephone and **managed to find the reason for patient's insulin being discontinued.**" **Discharge Nurse**

Common themes

Vision and Leadership

Our initial work with local places has shown that all have a shared vision across services - about the need to have access to a single record of individual patient information - enabling improved intervention to support patients' health outcomes.

Whilst there are clear visions in place for the IDCR and its purpose, there isn't always clarity on how this vision and ambitions for the IDCR links to the overarching local vision for Health and Social Care integration. This may be something which is seen as implicit, but could benefit from being explicitly set out within relevant partnership documents and discussions.

Leeds Care Record strapline
Shared information = better care for you

North West London
Improving the quality of care for individuals, carers and families, empowering and supporting people to maintain independence and to lead full lives as active participants in their community.

Bradford and Airedale
The aim is to deliver the right care, in the right place, first time for local people facilitated by effectively sharing information across general practice, community nursing, therapy services, mental health, social work and intermediate and secondary care support services.

BNSSG Connecting Care programme
Our common vision is that, by sharing information securely and effectively, we will make a lasting contribution to the health, well-being and opportunity of our population.

However, even with successful approaches to developing a vision to integrate health and social care and improve information sharing, not all areas have commenced work on integrating social care information with health information.

There are a number of possible reasons for the sharing of social care data not yet being part of the 'Integrated' Digital Care Record, which may include:

- Available funding streams being directed at healthcare services and not social care services

- Upgrading of management information systems within adult social care

- Lack of understanding of how the health and social care systems work together

- A lack of resources and support to help patients at key transition points between health and social care, such as discharge from hospital

"We all understand that there's a big prize at the end of the day: a fully integrated digital care record."

Dr McElligott, Bradford District Care NHS Foundation Trust, Medical Director.

Leadership

Another key local driver and common factor identified was the role of senior managers in leading the case for IDCRs. Many areas identified that strategic leaders have been a key enabler in driving forward projects, through promoting and supporting integrated visions and encouraging buy-in and support from partners.

These leaders share a number of critical qualities, which include:

- Appetite for risk

- Ability to answers direct question

- Asking difficult questions of others

- Understanding the environment that they are working within - professional backgrounds fostered credibility among professions

- Focus and have the drive to push an agenda forward.

Relationships

Relationships between and across partners have been cited by all as a key factor in initiating an IDCR project.

Information Sharing Agreements and local protocols as relationship builders

One way in which these relationships develop is through the process of agreeing the purpose of their IDCR and developing any Information Sharing Agreement (ISA) which underpins it. An ISA provides a format in which partners can set out exactly what data will be shared and how, but its value is also in the shared experience of debate and decision-making. The process of developing an ISA in partnership does more than just provide a gateway for the sharing of patient data at the end, as it also secures 'buy-in' from key stakeholders and helps partners build the trust and relationships required to articulate and agree a shared vision and outcomes.

ISA development across Leeds

Leeds has always been transparent about its approach to sharing information - and much work has been done and continues to help support practices and the patient understand the implications should they wish to opt out. The development of the ISA took about a year to complete, including work from each partners' legal teams to agree the content, before the city-wide roll-out of an integrated digital care record could begin.

Initial conversations with partners were held to understand the concerns and incorporate the findings to develop a city-wide information sharing agreement. This honest approach from the outset has laid positive foundations to ensure open and honest communication throughout the ISA's development.

The annual review of the ISA took place in October 2015 and resulted in confidence across all organisations that the ISA remains legitimate and appropriate for the current use of the Leeds Care Record.

Building relationships at all levels

Relationships between strategic leaders from health and social care have been built at board level through an understanding of each other's priorities and aligning these for a common purpose - to achieve better outcomes for patients and to provide better value services for local citizens. This has enabled problems in the achievement of priorities to be shared across the partnership.

The approach taken to building relationships in Bristol, North Somerset and South Gloucestershire (BNSSG), was one of starting small and 'going where the energy was'. So the initial partnership of 4-5 partners was not made up of a pre-determined group, but rather consisted of those organisations who were enthusiastic about the scheme and wanted to be part of it at the start. The growth from this initial group to a partnership of 17 organisations was driven at first by informal relationship building activity, focused on building trust and mutual respect. Communicating what the Connecting Care partnership was doing also played a key role, helping to build enthusiasm for the programme and reaching out to other local organisations.

A phased approach (to engagement) was used, as it was accepted that not everyone was at the same point. This meant that local organisations were able to take up a 'place at the table' in partnership meetings without a requirement to commit funding or invest in technological development. As the partnership grew, and the programme entered a procurement phase, the act of doing the procurement provided focus for further, formal relationship building, strengthening existing partnerships and generating good relationships across board, project team and technical levels.

In Bradford, the close relationship between partners has supported effective collaborative work on the IDCR. They recognised that a key contributing factor included partners' use and affinity for the same electronic record system - SystmOne. The role played by having 'software in common' went beyond just the practical benefits, and avoiding any debates over whose system should be adopted by other partners, to also providing a common connection and shared starting point between partners across the area.

Project Managers from different agencies, at an operational level, met regularly throughout the delivery of the IDCR programme in Hillingdon. This cross organisation project group looked at both the development of the MIG itself but also developing organisational structures that support the use of the MIG. Problems that came to light were shared and tackled quickly by the whole group resulting in ownership of both issues and solutions.

Relationships between healthcare providers and the software providers were also cited as important. In BNSSG, they attribute part of their success so far in finding a software partner (Orion) that 'gets' integration and was willing to work with them on a phased, benefits realisation approach.

Leeds also highlighted that good relationships and trust developed over time, enabling further integration across health and social care.

Communication

Communication with relevant stakeholders at all stages of decision-making has also emerged as integral to developing an IDCR and ensuring all stakeholders are engaged with the service integration journey. Key messages about the purpose of information sharing are particularly important when communicating to the general public on local and national information sharing initiatives.

In Hillingdon, GP Practices were engaged individually by the project leads, with time taken to explain the details of the scheme and the need to inform patients about data sharing. This enabled any individual concerns to be discussed and responded to. In addition, workshops on information sharing and patient consent were run for GP practices, and a leaflet was developed to help doctors talk to patients about the data sharing plans. Support was also provided to practices to ensure they were activating their agreements and liaison was undertaken with the Urgent Care Centre. This approach took some time, but has resulted in high levels of participation in the data sharing arrangement.

A similar approach was taken in Leeds, with the project team taking the time to engage individually with GP practices and Practice Managers - listening and responding to their concerns. In some cases, this process involved a number of visits before a final agreement could be reached.

In BSSNG, direct engagement with GPs was supported by communications activity including the use of partners existing newsletters to GPs to provide information about Connecting Care and the GP meetings being organised.

It is clear that the development of a joint communication strategy also ensures a consistent message from all involved in the promotion of the project. Communication with both clinicians and patients must be transparent and consistent. For example, in Leeds everyone receives the same communication about the benefits of the Leeds Care Record and how it works. There is a dedicated website and direct, targeted social media to reach patients who may not use traditional media. Posters and leaflets are displayed in key places across the city – including GP practices and waiting areas in hospitals. When looking to roll-out the use of the Leeds Care Record across the City, use was made of the website and local media, such as the Yorkshire Evening Post newspaper and Look North regional news programme.

A joined-up approach to communications can also be seen in the work carried out by Leeds City Council to incorporate messages about the roll-out of the Leeds Care Record into the leaflet 'How we look after your information', the development of new scripts for Contact Centre staff regarding consent and opting out of information sharing arrangements, and the introduction of a recorded message regarding information sharing which anyone calling the Contact Centre hears before being put through to a Customer Services Advisor.

Partners across Hillingdon also developed a joint communications plan, which included regular IT updates. This approach worked well in raising awareness of what was planned (for example, the primary care IT team knew when the new system would be deployed) and in managing clinicians expectations t when the system went live.

The impact of national data sharing initiatives on communication

National awareness raising campaigns and associated media coverage about national data sharing programmes (such as Care.data and the Summary Care Record) have impacted on the general public's awareness and understanding. As such, the level of this awareness and the impact it had on people's decision making varied from areas to area.

In order to support communications with GP practices, partners in Bristol, North Somerset and South Gloucestershire (BNSSG), developed materials to help communicate about the project and to explain the difference between local and national data sharing initiatives. The materials were designed to support GP Practices to respond to any questions they might get about the local data sharing scheme – Connecting Care, and the different types of 'opt-outs' available to individuals.

Communication challenges

In Bradford and Airedale, consideration was given to adopting the use of implied consent to information sharing, but public concerns arising from the national care.data programme and its use of implied consent caused a level of caution to be exercised by partners. This also stalled progress.

Mixed messages from media coverage on the different national initiatives about the sharing of data have caused public confusion. Bradford are therefore looking at different approaches to communicate to the general public about the introduction of implied consent for their direct care to ensure clarity of message.

Some national drivers for technological change in the sector have also affected the timing of communications. For example, health service providers across Bristol, North Somerset and South Gloucestershire had not implemented the National Summary Care Record as early as other areas. So, when they were advised by the Health and Social Care Information Centre (HSCIC) to issue a letter to inform residents about the introduction of the National Summary Care Record and what it would mean for the public, they used the opportunity to tell residents about the Connecting Care programme. Even though communication plans had been brought forward, the team discovered that people were happy to have a number of initiatives explained within one communication. The success of this combined communication was helped by the use of separate sections in the letter for the different national and local data sharing initiatives, and liaison with both the Patient Advice and Liaison Service (PALS) and Patient and Public Involvement (PPI) leads to review the letter before it was issued.

Engagement with partners, providers and patients

All areas interviewed told us that it was important to identify the key partners and stakeholders that would need to share information at the planning stage, to enable integration of health and social care data.

From the outset, Leeds Care Record has engaged with patients, stakeholders and service users to ensure they are at the heart of the project. Leeds ensured that Councillors and the local medical committee were briefed on a regular basis. Patients were also engaged from the beginning of the project, including the local Healthwatch organisation. For example, regular meetings are held with a dedicated patient group who have helped provide guidance on a wider reaching patient engagement and to develop the communications material and plan. There are also regular updates to Leeds North Clinical Commissioning Group Patient Assurance Group, the project lead for the city. The team has also met many of the GP practices patient representative groups to inform them of the project.

For specific areas of development, the team have commissioned Leeds Involving People to engage with patients and service users to help inform the project. A number of methods have been used, including; surveys, face to face interviews, focus groups and piggybacking network events. All reports are available to view on www.LeedsCareRecord.org/news

As part of fair processing we need to inform individuals about Leeds Care Record. Ensuring appropriate visibility and communication allows patients to make an informed decision if they wish to opt out of the initiative. This has involved a multi-platform communications and extensive engagement all available to view on the website www.LeedsCareRecord.org

Quotes received during independent engagement run by Leeds Involving People[11]:

> I'm sick of going through my details again and again, so good

> It would make my care easier

> Can't believe they hadn't done it sooner. Yippee

When engaging with partners in BSSNG they have found it is important that the shared outcomes expected for patients and citizens are at the forefront of every partner's mind. In BNSSG, they actively sought to "encourage a non-organisationally-centric approach" when it arose, and encouraging partners to talk about the aims or benefits of the programme in terms of "what's in it for the greater good of the patient".

However, the potential for Connecting Care to help organisations meet their own objectives has been used to help engage new partners. For example, in response to the directive from NHS England to commissioners and providers to have an IDCR road-map, BNSSG sent out messages to their networks to say "what are you doing about this – do you know Connecting Care can help with that?". This has generated word-of-mouth messages which are helping Connecting Care to sell itself.

All four areas also identified that engagement with GPs was vital to the use of an integrated digital care record, as GPs have a key role to play both as the Data Controllers for their patient records, but also as a key point of communication with patients about data sharing.

Partners across Leeds engaged with GPs on a one-to-one basis to identify any concerns and address them, either during the meeting or through continued communication at a later time. Using a personal approach like this can be time consuming, but the participation of all 107 GP practices in the Leeds

Care Record demonstrates that it has been worth the time invested as it has ensured engagement and participation with the Leeds Care Records by all GPs in turn covering approx. 817,000 patients.

A similar approach in Hillingdon by the CCG has resulted in around 90% of GP practices in Hillingdon having signed up to the data sharing. GP Practices were engaged individually, with time taken to explain the details of the scheme and the need to inform patients what the data sharing would mean for them. In addition, workshops were run for GP practices on information sharing and patient consent, and a leaflet was developed to help doctors talk to their patients about the data sharing plans. Support was also provided to practices to ensure they were activating their agreements. This approach took some time to carry out, but has resulted in high levels of participation in the data sharing arrangement.

Working with the hospital trust in Hillingdon

Engagement of hospital staff in Hillingdon in the development of the IDCR was managed and delivered by the Hospital trust, rather than the CCG. This meant that the hospital took responsibility for training and involving clinicians and working through the consent process. This activity was supported by the CCG, which shared the documentation developed for engaging people in the Primary Care sector with the hospital trust. These documents were adapted to reflect the different audience, namely hospital staff. The information sharing guidance developed for GPs was also used as the basis for a similar training programme for the hospital consultants.

GP engagement was, and is, an important element in BSSNG as well. Before starting to engage local GPs in BNSSG, the partners spoke to the Local Medical Council (LMC) and the three local Clinical Commissioning Groups (CCGs) to ask for advice on the best ways to engage GPs and how they should do this. Locality managers within the three CCGs held meetings for GPs in geographical clusters of

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[11] Leeds Involving People represents the independent voice of people through the promotion of effective involvement. Find out more at http://leedsinvolvement.org.uk/

practices and one-to-one follow up meetings (either in person or on the phone) were organised in response to queries. This direct engagement was supported by the use of partners existing newsletters to GPs to provide information about Connecting Care and the GP meetings being organised.

Training

The areas we met with have approached the need for staff training in a number of ways. Hillingdon has involved the Hospital Trust and the CCG in training and support for hospital staff to work through any concerns about the consent process. The information underpinning this training was developed using documentation used for engaging people in the Primary Care sector with the hospital trust. These documents were then updated to reflect hospital staff, and the information sharing guidance developed for GPs was also used as the basis for a similar training programme for the hospital consultants. To address the need for training with new staff, it has been embedded into the induction process and an online training module is available for GPs to fit around other work commitments.

Using a professional trainer – Leeds

To increase system use, Leeds employed a trainer, as part of their project team. They have recently increased the number of trainers to support service change, taking into account the feedback received from professionals as to why they have not been using the system, for example GPs working 15 hours per day and therefore struggling to implement new ways of working.

Start small and grow in stages

Each area has taken a stepped approach to developing an IDCR. Change was initiated by using pilots across small geographic or operational areas, where conditions were most conducive and receptive to change. The recognition of success achieved in these discrete pilot areas is citied as a key factor in encouraging other partners to come on board and so enable change to be rolled-out across the wider area and in other operational areas.

The two stage approach in Bristol, North Somerset and South Gloucestershire (BNSSG)

Partners across BNSSG recognised that funding for their IDCR programme would be significantly limited until a case for change was proven. The management group decided early on that they needed to take a two-stage approach.

In the first phase, a limited system was rolled out to 500 users to support unplanned or urgent care needs. This first stage was carefully evaluated and time spent establishing the impact, benefits and learning from the initial development.

Through this, the programme leads built a convincing proof of concept in order to bring others on board, whilst early mistakes were learned from before extensive investment in the system. As a result, a business case was written for the second stage of development that provided accurate benefits and cost savings. Partners accepted the case for change and the Leadership Board signed it off successfully within the timescales for this phase of the programme.

Recommendations

The areas consulted have all taken very different approaches to the implementation of an Integrated Digital Care Record with some common themes encountered in terms of progressing programmes of work. In conclusion we would recommend that the following should be considered:

- **Start small -** through pilots or phased approaches, messages about and evidence of benefits for a digital integration of patient records can be captured and developed, incorporated into other aspects of the project such as business cases, funding bids or stakeholder engagement plans. Initial teething problems and concerns around security of information can also be addressed and before a full roll-out of the record

- **Stakeholder engagement –** this needs to begin on day one of any project. This should include service users, Councillors, the local medical committee and Healthwatch, as well as partners, providing regular updates on progress and developments. Individual engagement with GPs is also crucial and must start early. Whilst this may be a time-consuming approach it has been shown in local areas with high opt-in levels to be worth the time taken. Enabling partners to to ensure all concerns are addressed and manage a significant risk to the effectiveness of any IDCR record built around GP records – namely if the GP does not give consent to their patients' information, then no information is available for other services (even if patient's have consented).

- **Securing funding –** Local places areas have developed successful bids for national funding streams, such as the Safer Technology Safer Wards and Tech 2 fund, to provide the necessary additional resources required to develop a programme to pilot and then roll-out on a larger scale, an integrated digital care record. Consideration should be given to securing local sources of funding in addition to any national 'tech', transformation or innovation bids, as this can help cement partner buy-in and sustainability.

- **Embrace the process –** Areas using Information Sharing Agreements (ISA) as part of their IDCR project, have told us that they find this a challenging and lengthy process. Underpinning these difficulties is often a mixture of risk aversion, differences in the interpretation of legislation, and cultural differences (within and between partners). However, the framework which the development of an ISA provides can help to structure partnership discussions. Developing this framework collaboratively can provide the driver for partners to gain clarity and reach agreement on both their high level vision for sharing information, and practical arrangements to support data sharing. To help take some of the confusion and concern out of developing Information Sharing Agreements, local areas can consider using 'Plain English' guidance and templates developed by the Ripple Programme.

- **Be clear on what you're doing and what you're not –** Communications of national initiatives, such as care.data, have impeded developments at a local level when introducing local information sharing and integrated health records initiatives. The general public still has concerns about how information will be shared in response to media activity in publicising how initiatives like care.data will work. Different areas have developed innovative methods to reach out to the general public to canvas public opinion on the sharing of their information. This has enabled areas to pitch their communications to address noted concerns on information sharing initiatives. Local places have also started to develop materials for the public and stakeholders which aim to make clear the difference between local IDCR initiatives and national data sharing programmes such as the Summary Care Record. These messages need to be tailored to local areas, but should be built on to provide consistency in messaging across local areas, and potentially at a national level.

- **Harness talent and foster spirit –** Take time at the start to gather a talented project team, and work on development of a collective spirit amongst the membership of partnership groups at operational and strategic levels. Ensure that you use the procurement process for any software partner to help you identify and choose a provider who understands your needs as a place by clearly defining not only your system requirements in procurement specifications, but also your wider approach to transformation and change management.

- **Focus on the end game –** 'Organisationally centric' thinking should be challenged at every opportunity through a focus on benefits and outcomes for the patient. Time should also be allocated to identifying, monitoring and evaluating benefits from the start and updated throughout the life of the project – these benefits will provide the basis for funding applications and for buy-in from stakeholders.

"Joined-up care is better for everyone. It gives people a better experience of care, helps them to stay healthier for longer, and to recover better if they are ill."

Care Quality Commission (CQC), 2009

Further information

More information on the four areas covered in this case study, and their approach to IDCRs, can be found in individual 'mini case studies' for each local place on www.informationsharing.org.uk/hsc

Further information can be found on following websites:

Bradford, Airedale, Wharfedale and Craven

IDCR Case Study by HSCIC

https://www.england.nhs.uk/digitaltechnology/wp-content/uploads/sites/31/2015/09/idcr-success-story-bradfrd.pdf

IDCR presentation for Digital Health and Care Alliance event (April 2015)

http://dhaca.org.uk/wp-content/uploads/2015/01/IDCR-DHACA-Presentation-2015-04.pdf

Bristol, North Somerset and South Gloucestershire (BNSSG)

Connecting Care webpage and supporting materials (opt-out form)

https://www.bristolccg.nhs.uk/about-us/how-we-use-your-information/connecting-care/

Connecting Care case study by Orion Health

https://orionhealth.com/media/case-studies/connecting-care-bristol-north-somerset-and-south-gloucestershire-row.pdf

Connecting Care: Our story so far, presentation for the Spring/Summer 2014 Health Insights event

http://www.healthinsights.co.uk/content/archive

Connecting Care: Our story so far, presentation for the June 2015 Bristol Health Insight event

http://www.healthinsights.co.uk/content

Hillingdon (North West London)

Hillingdon CCG

http://www.hillingdonccg.nhs.uk/

Integrated Care overview and supporting documents (including information governance communication materials for patients)

http://www.hillingdonccg.nhs.uk/integratedcare

Leeds

Leeds Care Record

http://www.leedscarerecord.org/

Leeds Care Record communications materials

http://www.leedscarerecord.org/resources-2/

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