Health and social care integration
Confronting the challenges
This research report has been produced for Eduserv’s Executive Briefing Programme.

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Why write this? An introduction

Integration of health and social care is one of the Government’s major programmes of reform. At its heart, it is about ensuring that everyone can get the right care and support, whatever their needs, at every point in their care journey. But it is also about efficient, joined-up and digital services.

The track record in the UK of joining up these vital service areas across the NHS, social services and the voluntary sectors using technology is not good. Projects are often too narrowly defined around existing organisational structures and professions rather than the individual, place and ‘whole system’. Case studies appear almost daily demonstrating better coordination, simpler and safer care pathways, faster decisions, and improved efficiency, but they are often too narrow or not easy to generalise and to scale.

The emphasis on having a single, all-embracing health and social care record is fraught with technical challenges and issues of public trust. Resources, policies, governance, standards and priorities are just too fragmented for integration to work.

This report is therefore intended for a wide audience of decision makers, influencers and digital leaders involved in the care sector. All need to come together to remove the barriers that have hampered change in the care sector in the UK. Targeting a report at one group of professionals will not capture the ‘whole system’ changes required.

For example, pooling health and social care resources at a community level and targeting these on individual service user outcomes is essential. It will not only improve services, but it can also reduce the untenable pressures on over-stretched primary and secondary care services. Yet the way budgets are currently set and administered can act against this.

Many previous health IT programmes in particular have received poor press, failing to meet expectations. They typically concentrate on digitising services, not on creating new digital service models. Even basic information sharing between health, social care and the voluntary sector is currently problematic, with
different standards and expectations of what is, and is not, allowed. Concern for patient safety, data privacy and ‘access for all’, leads us into information governance complexity with good intent, but which results in inertia or paralysis.

Linking a core care record to related data would create flexibility, yet ensure appropriate controls and security exists at every level, with the service user truly in control of their data and how it is shared, across a wide spectrum of services – the ‘whole system’.

There is room for optimism. It will be health and social care integration which will define and shape the role of technology in future public services design more than any topic – driving innovation, efficiency, service improvement and better management of risks. Devolution, shared budgets, new technologies and digital solutions, coupled with strong political and public support for change, are creating the impetus. Increasingly, local authorities and the NHS are working together on transformation programmes and local, place-based, ‘Sustainability and Transformation Plans’ (STPs) to improve the quality of care, wellbeing and efficiency. But that will not be enough.

This is the first of two reports. This report, Part 1, focusses on the context and what needs to change. Part 2, which will be available this autumn, will build on this and develop the digital standards, architecture and technical opportunity, to redefine how digital and technology leaders need to think and work differently in support of new models of care services.

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His work has included social care programmes in Europe and he speaks and writes on digital health and social care for a number of organisations. Since becoming a digital consultant, Jos has run the Eduserv Executive Briefing Programme, looking at digital opportunities for local government in particular.
Executive summary

This report (Part 1) is written for all those who have influence and a part to play in shaping the future of integrated health and social care: policy makers, senior executives, CIOs and politicians in the health and social care sectors. It is a broad audience because the nature of the challenge is broad and requires wide and committed support for change.

It is arguably health and social care integration which, more than any other area, will define and shape the future of digital public services. The report provides context and guidance on what needs to change in order to make faster and more sustained progress, given a UK history of problems and obstacles.

We believe that the key challenges do not lie in the technology, but in truly placing the individual service user at the heart of service design, dealing with the cultural and governance implications of this. The service user needs to be more in control – of their data and how it is collected and shared and of how services are linked to reflect individual needs and preferences.

We also believe that this new model must put much greater emphasis on the importance of place-based delivery, at a local level, linking a wider range of care services together to reduce pressure on national primary and secondary care. This should be supported by national policy, standards and service components, not the reverse.

This report is based on research across multiple sources, including government, professional bodies, expert witnesses and independent studies. In the coming months we will be supplementing this work with a series of blog posts and interviews.

A second report (Part 2) will be published in the autumn and cover the implications on digital architecture and technology, aimed at CIOs and digital leaders.
Putting the service user at the centre

The ‘service user’ should be at the centre of care solutions and ‘own’ their records

Placing the individual service user at the heart of health and social care service design means full access to records and data, including being able to add and amend data. This can reduce unnecessary contact, cost, errors and avoids a ‘one size fits all’ approach. It requires a redesign of how national services (mostly NHS and Social Services) work together and with local service providers. It requires clear, mandated policy on data handling, joint governance, resource pooling, and a shared service user identifier such as the NHS number.

Culture, not technology

Cultural and structural barriers within health and social care need to be addressed before the technology is implemented

One of the main challenges lies in cultural differences between health and social care. There are deep rooted differences in language, governance, processes, systems and performance management. Health and social care must become equal partners, along with the community and voluntary services, if we are to achieve effective integration and reduced burden on primary and secondary health care. That will require fundamental change to cultures.
The professionals

The role of care professionals is changing, requiring new structures to make best use of the resources

The growth of personal digital tools and information means that the traditional care professional is no longer the sole expert. Powerful professional interests resist change to service models and resource allocation. General Practice (not necessarily GPs themselves), if resourced, could commission social care and alternative services for wellbeing or recovery. A network of support around the individual’s need, locality and preferences is required that includes family, friends, volunteers, community support and charities.

Place matters

A broader mix of care services requires design of solutions around the location

The argument that all of health and social care can be run as a national model administered locally does not work. Locally defined care pathways and support can better reflect individual need and preference. This approach is also lower cost and more flexible as needs change. Integrating a variety of local community and voluntary support will reduce the untenable pressure on national services. National services, programmes, policy and standards need to be franchised and federated for local implementation.
Data, systems and standards

Shared and linked information systems, with a core single record, are fundamental

Health and social care service records are currently incompatible, data is of mixed quality and paper files are still commonly used alongside electronic records. Creating a single shared core record, with a shared common identifier is essential. But a ‘whole record’ available everywhere is not the answer. Linking data securely across related systems, care services and teams, using standards for data handling is needed, with the individual service user determining what is shared when and how at all times. This will allow a richer set of systems and services and, with the user in control, improve sharing and data quality.

Funding and budgets

Budgets need to be pooled and realigned

Sharing resources across the care services makes sense, but is one of the key challenges of combining health and social care provision. Funding is locked in heavily protected siloed budgets. Funding regimes deter sharing and targeting investment on prevention and community based care services, yet this could net significant savings. A more holistic approach to care budgets is needed, with necessary controls and transparency. This will reduce demand on the more expensive front lines services, enable greater self-service and choice, and speed up the delivery of services to service users.
Historic challenges – Learning lessons

Once upon a time (from 1968 to 1988), there was a Department of Health and Social Security (DHSS). National policy for health and social care was linked and prior to the internet, the UK was trying to tackle the problem of giving clinicians and administrators better access to anonymised performance and management information.

Yet despite the power of technology since then, from the internet to consumer technologies including the mobile phone, and the amount of change in other sectors, progress has been at best cautious and in reality slow and disjointed in health and social care. Numerous large-scale NHS projects have floundered and alienated practitioners, and a range of challenges remain today:

- Too little join-up between social care, GPs, community health organisations, mental health and hospitals which continue to function as separate services with clunky ‘hand-offs’ interfaces, fragmented budgets, incompatible data, separate projects, buildings, policies, investment and strategic thinking. Even the professional language used is different.

- There are many national organisations trying to address the challenge, especially in the health sector (look at the list of membership bodies on the National Information Board). Trying to coordinate what they all do is a complex task in itself.

- Health and social service records are not only incompatible, but evidence suggests data quality is a barrier, especially in social care departments, with little focus on how this can be resolved in the interests of better care.

- Frequently patients and carers have to navigate and coordinate between services themselves, compensating for the poor communications between the various agencies and support services, even within the NHS itself.

- The continuing dependency on paper records and manual recording, and the partial move to electronic records, has made information management even harder. Yet some hospital trusts and many social care services have moved entirely to electronic records. Silos of information create a major barrier to better care and a reluctance to record electronically.

- The benefits of ‘state of the art’ medical technology and advances are held back by administrative systems in health and social care – inefficient handovers between services, scheduling aftercare support and tests, and avoidable contact which take professionals away from more important work.

- The well-meaning but often unproductive and fruitless debate about data privacy and systems security results in continued fragmentation, single supplier dependency, work-arounds and poor use of essential data, to the detriment of service users.

- Following the 2012 Health and Social Care Act, there is a growing number of non-NHS qualified care providers, but a lack of recognised standards makes it hard to ensure effective exchange of data, sharing of systems or pooling of resources.

- Powerful professional interests resist change, sometimes for well-intentioned reasons, sometimes to protect professional silos. Pockets of innovation exist, but these are not generalised or scalable.
● Too much intervention only takes place at a point of crisis and is designed to do so, with too little emphasis on and investment in prevention or early intervention to align to changing user needs.

● Whilst Health and Wellbeing Boards are beginning to oversee both health and social care – governance, ownership, budgets and decision making are still too fragmented and not co-joined around individual needs: wider care services, location and changing conditions.

● A plethora of programmes and projects – the Better Care Fund, Pioneers, Vanguards, Personalised Care 2020, all generate good practices, standards and solutions, but mostly driven from a centralist and health care perspective.

● Deeply embedded processes that have grown over many decades, often with good intent but with narrow professional focus, out of step with digital practice and designed by the delivery organisation for its own benefit.

There has been significant progress more recently, but mostly in specific areas where innovative organisations have got on and done something, perhaps out of frustration and despite the system. Integrating health services is hard enough, let alone trying to do so across local government and community care services. The UK needs to look at international best practice – such as Sweden’s success in reducing cancer treatment times from 28 days to five days (with plans to reduce to less than a day). These come from a holistic view of care and realigning governance in the system around the service user.

Talk to anyone who works in A&E and they will tell you about the number of unnecessary visits they receive and how these could be better dealt with. The same happens in social services and in GP surgeries. Yet these are the most complex, expensive and hard pressed services. These resources must be deployed more appropriately by taking a whole system view.

This year, the government announced that £4.2bn will be spent on bringing the NHS into the digital age – paper-free, kite-marked NHS and social care apps, digital records, click-and-collect prescriptions, free Wi-Fi in hospitals and above all, citizens having access to personal data they can control and edit, wherever they are, shared with care professionals.

This will help, but must not repeat the mistakes of the past (too central, largescale and health focussed). Success will depend on learning lessons about where and how government intervention should apply, changing boundaries of responsibility and autonomy between the professional services, amalgamating resources around the service user and striking a new and more effective balance between a fragmented free-for-all and an imposed ‘grand plan’.
The terminology and language used by health and social care sectors is very different. Health as a sector talks about ‘patients’ and ‘health informatics’. Social services talk about ‘clients’ and ‘information technology’.

This report (and most others) puts a strong emphasis on placing the patient, client, user, individual, citizen, or customer at the centre of future digital design of care services. But what term should we use? ‘Customer’ is questionable; customers usually pay for a service which they choose, but for social care some interventions are unwanted but necessary. It is also questionable whether or not someone in hospital sees themselves as a customer.

So this report uses the term ‘individual service user’, to emphasise that people use a range of services, and that design principles need to be set universally, from the point of the user – irrespective of whether they are a patient, client or a paying customer. Moving away from using the words ‘patient’ and ‘client’ where we talk about designing digital solutions won’t be easy, but would help to break down language barriers.

Digital design can draw together a wide net of services, tailored to the individual and flexible as circumstances change. A ‘whole system’ view will bring numerous benefits, including speedier discharge from hospital, better care in the community and even avoiding the need to go to hospital in the first place.

### Whole system place-based care

- **Place-based**
  - Local services
  - Housing needs
  - Day care services
  - Family
  - Friends
  - Community support
  - Mental health
  - Out of hours services

- **User-centered**
  - Volunteers
  - Private sector

- **Flexible and Safe**
  - Travel options
  - Pharmacist
  - GPs
  - Nurse
  - Consultant
  - Physiotherapy
  - Ambulance

- **Whole service**
  - NHS 111
The public are in favour. A survey last year by NHS England showed that people across all sectors of the population want access to online care services and their personal budgets. There is frustration with our out-of-date health and social care service administration, not fear of depersonalisation in the move to digital.

Most people are comfortable with booking and ordering services online. Health and care services should be no different, and brought together in ways that suit all of us as service users, not the professional teams running those services. The majority of us bank online – and we expect to have access to our data – our bank statement and record of receipts and payments. So why do we still even debate the access and ownership of our electronic health and care records? And if you do a ‘Park Run’ on a Saturday, your race results, position and data will be sent back to you electronically before you even reach home. Medical test results could be as quick in many instances; the process of responding to adhoc information demands and disseminating test results and communications to service users should take minutes, not days or weeks.

Health and social care records should be accessible and owned by the individual service user; easy to navigate, easily understood, with links to related information and support. This includes ensuring that minority groups and those with disabilities can access their data in the same manner. Sometimes it feels as though the professionals see themselves as the user. At the same time, a redesigned service cannot be built as a ‘one-size-fits-all’ digital model.

Yet to create a single, complete and centrally held health and social care record, available everywhere, will be technically challenging, if even feasible. What is needed is a core record shared across the related professional groups, using a linked data identifier (e.g. NHS number) with suitable ‘consent systems’ to connect other services and data sources. This could then form part of a wider ‘virtual’ electronic record, controlled by the individual. There are just too many data identifiers at present.

This does not happen because care professionals worry that we will misunderstand our data, or what they write about us in our records. It is not because the technology cannot make it possible. NHS England is working with the professions to ensure this becomes more commonplace, looking at areas of technological safeguards necessary to allow patients not only to access records, but also to add to them.

At the same time, we cannot take public trust in digital for granted. Data breaches or failure of care if caused by perceived poor digital practice, will undermine public trust.

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**Haughton Thornley Medical Centre** in Greater Manchester was one of the first to make GP records available online to patients. This includes consultations, test results and correspondence with other providers. With secure access, they have freed up appointments and reduced call volumes as patients go online to access test results and get information to understand them.

**MyMR (My Medical Record)** project run by the University Hospital in Southampton also allows patients to access an online journal of their care, communicate with clinicians directly, view and book appointments, see test results and more. Supporting information relevant to the patient’s condition is also provided.
Public awareness will also need raising about how to access digital services and records – and the need for them to take care to protect their privacy and confidentiality. Placing the individual service user at the heart of design requires a much broader assessment of how those services should function. They need to prioritise personal preferences as well as service needs. They need to be accessible when and how the service user requires – and that includes resolving poor broadband and mobile coverage, especially in rural areas. And above all, it means the service user should be in control of and able to make choices about their care, including when and how they access services – and which services they choose to use.

This will reduce avoidable contact – visits to GPs, telephone calls and hospital admissions. It will create a new set of service access points which are more local and more relevant to the service user, and at lower cost. That will be particularly beneficial to those living in rural areas, minority groups and homeless and vulnerable people, for whom the current system can seem complex, remote and out of touch.

**Recommendations**

- A single health and social care core record should be owned by the service user, easy to navigate, add to, amend and understand.
- A unique identifier should permit links to related services, systems and data.
- Digital care services should be co-designed in a way that prioritises personal preference as well as service needs, with support from professionals.
- Digital methods should be used to allow a wide net of care solutions to be tailored around an individual, adaptable as needs change, and designed to protect privacy and confidentiality.
Effective management of LTCs is recognised as one of the greatest challenges facing health care. Care for LTCs accounts for 55% of GP appointments, 68% of outpatient and A&E appointments and 77% of inpatient bed days. In many cases commissioning of services for LTCs remains fragmented, and ‘care centered on the user’ is remote from the experience. There are a number of examples of ‘integration pioneers’ developing approaches to more effectively manage LTCs, such as:

**The Wellness Practice** (aka Health 1000): was set up by GPs in Barking and Dagenham, and Havering and Redbridge CCGs (Clinical Commissioning Groups). It is a new primary care organisation to support local people with complex health needs and long term conditions. The practice provides a comprehensive integrated service for patients, with a multi-disciplinary team of nurses, GPs, hospital consultants, physiotherapists, geriatricians, occupational therapists, social workers and voluntary care navigators.

The aim is to offer people support to feel more in control of their own care, whilst offering help to stay out of hospital and remain independent for as long as possible. (This is a pilot project supported by LTC Year of Care Commissioning Programme.)

**Supported self-management: NHS Scotland: Long Term Conditions Collaborative.** A self-management strategy for long term conditions in Scotland was launched in 2008. The continued investment in the Transforming Self-Management in Scotland Fund (administered by the Health and Social Care Alliance Scotland) provides opportunity for people with long term conditions to lead the way in partnership with community and voluntary organisations.

There is a general consensus that digital methods, with proper controls, are essential for effective, efficient and user-centred care services. Digital design can join IT systems together and so allow packages of care to be created across professional boundaries in ways tailored to the individual and which can flex as those needs change over time.

But the main challenges in doing this are not about the technology. They lie in cultural differences between the various health and social care professions, commissioners and providers, which result from separation of things such as budgets, performance measures, terminology, responsibilities, governance, and working practices.

The hard separation of care management is gradually being eroded, with Health and Wellbeing Boards now overseeing service provision in local areas and GPs taking on broader commissioning as part of CCGs. But these do not yet go far enough and there are still deep-rooted issues of authority and control which can result in a lack of trust. It was not long ago, for example, when pooling health and social care budgets was first being discussed, that the BBC reported a fear in the NHS that health funding might be misspent by councils on filling pot holes in roads.

The sheer size of the NHS and its positive public support can make it harder to make changes, especially in the boundaries of decision-making. Senior clinicians are powerful, presiding over services that protect us all and save lives. Social care by contrast is less well understood, smaller and not nearly as well rewarded. Yet the two must become equal partners if we are to achieve effective integration, and that will require culture changes to both services. Indeed, the financial pressure affecting primary and secondary care services could be significantly mitigated by greater support from and an investment in social services.

In fact, the care partnership needs to go well beyond this to embrace many smaller players in care provision in an area challenging the role of the traditional professional.

Leadership is key to bringing together professionals and to engendering a shared service culture between health service providers and across health and social care. Investing in ways to develop collective and collaborative leadership, together with IT strategists, will be a pre-requisite to a user centred approach and maximising technology opportunity. Contributors to this research indicate this is currently one of the biggest obstacles to true integration.

The Newquay Pathfinder is one of the government’s integration pioneers. Working with Age UK, older people on the programme received support from volunteers to assist with their care plan. During the first year there was a 30% reduction in non-elective hospital admission amongst the older people in the programme, saving £4 in health and social care for every £1 spent.

Recommendations

- Health and social care must be equal partners to achieve effective integration. This requires strong and independent leadership.
- Trust must be built between professionals, including those working in the voluntary sector.
- Governance of health and social care services needs redefining to be based on the needs of the individual and their location.
The professionals

The role of the traditional care professions and professionals is changing. The emergence of new technology such as smartphones, apps and wearable monitors, coupled with easy access to electronic information means that the well-informed service user can collect valuable data about their lifestyle or illness and then self-diagnose their condition or treatment. Furthermore, there is a growing network of voluntary and community services who support personal care and recovery, if the structures are in place to link these to individual need.

The idea of the health or social care professional as the sole expert, is therefore no longer valid. Also, the growing pressure on those vital, scarce and high-cost services needs to be reduced by allowing others to become more involved.

Whilst digital methods can potentially help to relieve pressure on primary and secondary care services, many care professionals are understandably nervous about this trend. Who, for example, is responsible if things go wrong? Some argue that an undue reliance on IT could also place patients at risk if the technology fails. Clinical safety must be paramount, and there is a culture of blame if care services make mistakes. Neither do care professionals want to see services becoming depersonalised through automation, nor people disenfranchised if they cannot or do not want to use IT. Health and social care services are traditionally dependent on face-to-face delivery, for good reason.

Yet when digital design is done well, it makes services more convenient and easier to access for everyone, with assistance where necessary. Costs are lower, so more can be done. Delivery can be faster and more productive, both for professionals and service users. Errors and mistakes can be spotted more quickly, with carefully designed alert triggers. The need for intervention can be predicted more accurately by using data trends and linkages. Care services can also be better designed and targeted for specialist needs and for minority groups, with the service user more in control of their options, service information and records.

Whilst there are risks in moving to digital delivery, these can be managed if there is a will to change. For example, it is usually poor data quality, manual paper-based methods and a half-way house between ‘old analogue’ and ‘new digital’ processes that creates risks, rather than the technology itself.

Professionals do need appropriate support in a move to digital methods. This includes greater digital skills and awareness in using systems across service boundaries, with a mix of consumer and specialist tools. But also

In Leicester City CCG they developed a pioneering approach to COPD (Chronic Obstructive Pulmonary Disease). Using a real-time communication system (telehealth), specialist nurse interventions and health coaching, they put the patient experience at the centre of care and encourage self-management.

The outcome has reduced hospital admissions per head from 3.13 to 1.02 per year, and also improved patients’ experience of care. Patient feedback suggested patients were more knowledgeable about their condition, more confident in managing it and motivated to change behaviour in a positive direction as a result of being involved in the intervention.
professionals need an understanding of the risks and the potential of new digital delivery models, not just to acquire new IT skills.

**General practice**

Care processes often start with a GP surgery visit, especially for older people. General Practice, (GPs and their support teams) if properly resourced and with access to care records and data analytics, could be the commissioners of a much broader package of care. They can often make faster and better decisions about alternative services for wellbeing or recovery, alongside medical care, potentially reducing the need for specialist health or social services.

GPs report that they lack the time and resources to undertake wider care planning and the proportion of the NHS budget spent on general practice has been declining steadily (from nearly 11% in 2005 to 8.5% in 2012 – Deloitte research shows). Changing the shape and form of General Practice could alleviate pressure. For example, larger practices which include more specialist services and links to voluntary and community groups, alongside traditional GP surgery services, could reduce cost, target scarce resources, increase speed of service delivery and make it much easier for the service user, so avoiding unnecessary ‘referral appointments’.

Also, since GPs are independent providers as well as commissioners of services, often in partnership with a range of new providers (such as Virgin, with over 300 contracts across the country already), there are also a range of vested interests to deal with.

GPs taking on an expanded role to provide a more integrated care is not a new idea. The Livingston Experiment started in the 1960s, where GPs working in the area were appointed to conjoined posts, working in both primary and secondary care, as a means to embed integration into the delivery of all health services within the town. The outcomes were not only shared learning and understanding between primary and secondary care, but also high patient satisfaction. The Livingston Experiment also inspired early data sharing and shared medical systems.

For example, a GP is often best placed to ascertain needs such as a disabled ‘blue badge’ or equipment in the home, but is rarely involved because funding lies elsewhere (with local and central government).
Community and voluntary sector

Health and social care delivery depends on a growing list of support networks - family, friends, volunteers and community services. This is widely recognised, but rarely formalised in care packages. How can these broader community based services be linked and connected without being intrusive, prescriptive or in competition with the traditional specialist professionals?

These services are often less structured and therein lies their strength, by being flexible and simple to deal with. Service users should be able to choose the portfolio of formal and informal services they need (or prefer) and determine what personal data can and should be shared as necessary. Policy changes are needed to enable this to happen, including appropriate levels of regulation, standards for data linkages and secure data handling guidance.

In Japan people live longer than in the West, and the growing elderly population places enormous demands on health and social care services. One solution to this has been a mix of support and activities for older people receiving care, even including encouraging people on day release from residential care to work in the community. For example, Honda employ older people in care to clean cars. Is this exploitation? Not if you ask the older people who look forward to the social interaction and purposeful activity.

There are also health and fitness benefits. But cultures in the UK would currently make this radical approach difficult for both industry and for care services.

Political support

Politicians have an important part to play in setting the policies and frameworks for user-centred care services, helping to change cultures and professional practices if these are a barrier to integration. They need to promote the long-term benefits, not just a ‘big picture’ or short-term popular policy. They need to overcome fears from previous IT projects and ID schemes, but ensure that ‘big project’ mistakes are not repeated. They need to resist the lobbying pressures of the big vendors and resist any blame culture when mistakes are made by care professionals. It is political will more than anything, that can overcome the inertia in the system and the vested interests.

A key area for politicians lies in resource allocation. Decisions about how services are designed overall and for individual service users are often determined by budgets and by a traditional sequence of recognised and funded processes. Far more money is spent on the NHS than any other care service, and this, coupled with medical research value, sponsorship and interests, therefore carries most weight. Even if £1 spent on social care could save £10 in health care costs it can be hard to move resources from health to social care. It is even harder to move money from health or social care into the voluntary sector. This is where political support for change is needed.
IT leaders

Finally, there needs to be changes in the IT profession across health and social care. Constant reorganisation in the health service in particular over 25 years has resulted in a patchwork of CIOs, Heads of IT and now Clinical CIOs (CCIOs) (no doubt soon to be accompanied by digital equivalents – CDOs and CCDOs). The same criticism can be levelled at local government, with CIOs and Heads of IT in every district, unitary, borough, and county council. This makes it harder to get a single strategic view of technology or to link digital programmes in a region, necessary to support the design of integrated health and social care services. Teams either need to be merged or they need to be streamlined and incentivised to collaborate - joining IT architectures and infrastructures (more of which will be covered in part 2 of this report).

Digital leadership, not just IT leadership is needed and these are not the same thing. Place-based digital leadership must support devolution and local governance, such as Health and Wellbeing Boards.

Case-study: Hampshire Better Local Care vanguard
“Bottom-up” transformation

Better Local Care is a partnership of local GP practices working together with the Southern Health NHS Foundation Trust, three CCGs, the voluntary sector and others in Hampshire. The project is one of the ‘New care model vanguards’.

GP same day access service: In Gosport they have developed a same-day appointment service which separates urgent care from care for long-term conditions. Calls to the service are triaged by doctors and nurse practitioners so that patients get to see the right professional at the first point of contact, or receive appropriate advice over the phone without necessarily needing to attend a clinical setting, thereby making better use of the resources available.

Working with care homes to reduce calls to emergency services: Having identified top care homes in the area who were high users of 999 where the patients were not being admitted, a multidisciplinary care home team from the NHS trust and South Central Ambulance Service worked with care home staff to provide training, support and therapy in a more joined up, timely manner. The pilot has resulted in a significant reduction in both the number of calls to 999 (by some 39.1%) and the number of residents admitted to hospital of some 22.3%.

Dr. Donal Collins, GP lead for Gosport, describes the partnership as very much ‘ground-up’ and puts their success down to having buy-in from across all parties. “We’re co-producing with commissioning, with patients, with the mental health trust and community trust to create a new form for the near future that will deliver a fully integrated health care system” he says.

Recommendations

● General practice (not necessarily GPs) need to take on more activities as commissioners of a broader range of care services; with the mandate, accountability and resources to do this.

● A wider range of care services and support needs to be recognised as part of a care package and linked in a way that supports the individual without being intrusive or predictive.

● Professionals will need greater digital skills and awareness to help design and develop new care pathways.
Whilst it is not sensible for every locality in the UK to work out and implement different models of health and social care, not every area is the same. Priorities will vary according to demography, rurality, community diversity and legacy position. In addition, whilst we want universal care with common standards across the country, and specialist resources pooled, not diluted, services also need to be joined up around where people live and work.

The challenge lies in finding a way to define national services at a local level, whilst ensuring that the most expensive and scarce professional services are only used when required, e.g.:

- Not using A&E if a GP or nurse can assist locally.
- Not going into hospital (or remaining there) for want of some community support.
- Not going into residential care because of a lack of home support of some kind.

It should be possible to create a map of all care services available locally, building on NHS Choices – whether part of a national service or not, private sector or public sector. Like Airbnb, you would be able see all services, book appointments, communicate directly with care professionals electronically, especially if requirements mean going out of catchment.

Digital methods overcome geographic and organisational boundaries, linking services such as health and social care to physiotherapy, planning transport to a hospital or day centre, home help, meals on wheels and more. This requires knowing more about the individual and their location and matching this to local services of all types.

For example, research repeatedly shows the impact of loneliness on health and social care needs of the elderly in particular – a lack of contact, reassurance, advice or access to telecare. The result is an untold number of visits to GP surgeries. Creating a network of local support – community help, clubs, contacts, shopping support, transport to events – can help to alleviate this all too common situation. It can also create more equality of access – socio-economic background is a critical factor and often related to place; for example, life expectancy in Beeston in Leeds is 11 years less than Moortown just 7 miles away.

Surgery Signposters is a support service running in the Gosport area for patients coming through the primary care system. The ultimate goal is to reduce GP appointments and A&E admissions by providing support from trained volunteers to ‘signpost’ local services available. Aimed at service users who need advice and support rather than clinical time, the service is also able to link-up individuals with locally relevant community groups, charities and voluntary organisations.

Large national services and government departments do not always quantify this part of the economic equation – doing everything at national or regional scale is more efficient on paper from a service perspective, but not necessarily from a whole system perspective. So national systems and services need to be implemented and brought together in a way which makes sense locally, without compromising the need for national standards and investment in national research or specialist services.
That requires an understanding of the network of services available, matched to individual needs and coalesced by shared budgets and data, overseen by the individual service user. National government sets national policy, standards, programmes and strategic ambition, but these need to be implemented locally in ways which reflect local circumstances. Just like a franchise model.

A place-based approach to care will also yield valuable data for clinical and social service planning, both locally and nationally. It will uncover geographic patterns of health and service performance and different needs which are currently obscured.

This can create a better understanding of the available mix of local services to reduce pressures on the most expensive health and social care services. Sharing data securely across agencies and support networks, means that a significant proportion of care can in practice safely be administered and delivered through self-service or community support services.
Design around service and location demands much greater openness – information and decisions cannot be locked into organisational silos, but have to be shared, (securely when necessary):

- Open systems, data and information.
- Single integrated view of service user needs.
- Pooled budgets and transparency about spend and performance.
- Shared governance and decision-making across services.

This requires a rethink about how data and systems are design, developed and delivered.

**Recommendations**

- An interactive map of all health and social care services available locally is needed, linking formal and informal support – accredited, referenceable and bookable.
- National systems and services need to be brought together locally through linked data and digital means with an easily accessible network of local support.
- Policy, standards and requirements need to be set nationally for safe local sharing of data and information – core record, related data, controlled by the individual service user.
- A significant proportion of care should be administered through self-service or community support.

**CASE STUDY**

Cornwall: Rural devolution with a ‘vibrant’ voluntary community

Cornwall is the first rural county to reach a devolution agreement (July 2015). Cornwall has specific challenges: it has a dispersed population and contains more residents over the age of 75 than the average for England, which is expected to grow significantly. However, it does have a ‘vibrant’ voluntary and community sector to support joined-up care.

Work is currently underway on developing a ‘place based strategic plan for the whole health and social care system which is both clinically and financially sustainable’:

**Consultation with the community:** Cornwall has prioritised consultation with key partners and local community, with surveys and community events held across the county. “It is really important that the future shape of health and care services in Cornwall takes into account the needs and aspirations of those who use them and this is an opportunity for residents to help achieve just that” said Dr Iain Chorlton, Chairman of Kernow Clinical Commissioning Group. (Press release March 2016).

**Developing plans for joined-up commissioning:** To enable a streamlined approach to securing packages of care and placement, and to enhance the discharge process and reduce delays of leaving hospital, Cornwall is developing plans for joined-up commissioning. For example, based on their strong links to public health, education services and social care, Cornwall Council will act as lead organisation for commissioning of community based children’s services. In parallel, NHS Kernow will take the lead on the commissioning of domiciliary care and care homes.

“Devolution of health and social care could enable more resources to focus directly on local patient care and outcomes, with more decision-making, budgets and accountability at a local level” Dr Iain Chorlton, Chairman at NHS Kernow (Press release January 2016).
Digital methods offer better ways to capture, validate and share critical health and social care data, but the service user must be in control at all times – able to view their data, to check for errors and to add their own background information.

We are close to a future where we all hold more data about ourselves in our smartphones and from wearable technology than has ever been held in our medical or care records. These personal systems and apps can help us to avoid health risks, diagnose symptoms early, learn techniques to manage long-term conditions and help to maintain a self-managed care plan. The data we collect should be able to form part of a future health and care record, if we choose to share it.

This means future care systems must, by default, be shareable, open and allow related data in standard format to connect. This is still a major obstacle, with barriers to joint information governance and data sharing. It is an area where government policy is needed to ensure simple, safe and mandated models for information sharing in the interests of the service user.

Support from health and social care specialists will be important to help us to link this valuable personal data to specialist care services and to inform care choices. We will not expect care professionals to reject this data, simply because it has not originated from within their core health and social care systems.

A single electronic ‘health and social care hub’ summary care record will be important, with a unique service user identifying number (why not the NHS number?) but it cannot be a ‘whole record available everywhere’ – that has been attempted in the past. A small core record shared and linked will permit approved connections to be made to other systems, services and electronic information pertinent to our condition, needs, location and preferences.

It is this linked data that can help to shape a more effective and personalised package of care – a Summary Care Record (96% of us have one already), is just the start of this journey. Currently, professionals do not always have the right data to support the care required, data quality is not guaranteed and creating links between related data sets is hard due to incompatibility of formats.

Paper files are still commonly used, and the current mix of different systems and manual/digital records, makes it hard to cross-reference data, share with service users or correct data inconsistencies and anomalies. This is partly why there are layers of repetitive data checks during the same episode of care when service users have to repeat basic data at different times to different people. Furthermore, there is confusion and concern about what can be shared, when and how.

Traditionally, health and social care systems operate as isolated silos and are propped up by a myriad of IT teams, training and support budgets, with separate IT strategies and information management policies. Each health and social care provider has their own set of systems, and in large hospitals there can be over 100 patient databases for different services and departments. If we are to achieve greater uniformity there needs to be a common overall digital architecture for core care systems, and the separate IT teams, budgets and strategies should be aligned, if not joined together across health and social care services.

Moving to a smaller set of common core digital care systems with standards for linking data and inter-connectivity across services, systems and specialisms, will allow a wider range of teams, professionals and carers to contribute.
data with fewer, easier and quicker checks to avoid mistakes. Simple fingerprint and smartphone recognition is now commonplace to confirm identity for payments and a similar mechanism could be used for health and care identity confirmation.

But privacy and security must be proved beyond doubt to ensure public trust in health systems. This is as much about perception as the reality of system controls and security standards. Whilst data risks usually come from paper-based records, not from hacked systems or lost electronic files, public trust will determine the success of digital services, and medical records in particular are said to be even more valuable to hackers than financial data.

There are recognised challenges in separating ‘primary purpose’ (personal) data and ‘secondary purposes’ (typically anonymised), not least in the public trust of how personal data is in fact used and shared. This is a challenge for the NHS to resolve, providing templates and guidance for core data as well as secondary data.

Care.data is a programme of work led by NHS England to bring together securely, health and social care information. Data sharing for purposes beyond direct care, only occurs if it would benefit the patient. Yet public opinion and some practitioners were not persuaded, particularly about how to opt-out and also about the checks and balances on who gets access to data.

Sharing our most private medical records must have a clear regulatory framework. Recently, health records were shared with Google to enable their sophisticated analysis to take place – well-intentioned, but again, not anticipating public perception or concern.

The primary concern must be service users and privacy. Different standards exist for secure email, file transfer and systems access in health and social care (such as NHS N3 network and PSN used across local councils and Whitehall), for no reason except historic or vested interests. The proliferation of mobile devices means the risk of electronic personal data being compromised is growing.

Simple and standard solutions to secure data transfer, such as data encryption are not being used universally, and should be. Imperial College London recently conducted a review of the NHS Apps library and found that nearly a third of all apps which transmitted personal data over the internet were doing so without any encryption.

Common, recognised and open technical standards also give greater choice of systems and apps, moving away from the situation where, to an extent, suppliers have had to dictate solutions in a vacuum. Whilst there need to be some core systems, open APIs (application programming interface) can allow much greater choice and a range of systems and data to be connected – optimised for specific parts of care services, for specific functions or personally chosen systems.

Standards will also allow greater transparency of where money and time are being spent in total in the care system, which areas are busiest and why, effective rostering of professional time and equipment use. We know there are enormous differences across the country in the prices paid by health and social care teams for equipment and medicines (e.g. in Lord Carter’s report in 2016 looking at the inefficiencies of NHS Trusts’ buying decisions).
We also know that specialist medical equipment and professional time is under-utilised simply because administrative care systems do not optimise the use of those resources – data not available when consultant needs it, test results too slow, medical equipment not used 24 hours a day because of partial scheduling systems, and so forth.

Part 2 of this report (which will be published this autumn) will cover more details of systems architecture and planning along with an open platform approach based on open and accredited APIs and apps.

Recommendations

- Future care systems should be sharable, open, and allow related data in a standard format to connect without having to be centralised. Privacy and security must be proved beyond doubt to ensure public trust.

- A single ‘core’ electronic health and social care record should use a unique service user identifying number, such as the NHS number, to allow other systems to be readily linked.

- IT infrastructure should be led by common, recognised and open standards, with defined open APIs. This will give greater systems choice.

- A ‘franchise model’ of implementation is needed (not a big ‘IT project’), with transparency and intervention where there is failure.

CASE-STUDY

HSCINI: Health and social care in Northern Ireland

Linking data to improve patient outcomes

Healthcare services in Northern Ireland are delivered through five Health and Social Care Trusts, responsible for the management of staff, health and social care services on the ground and with their own budgetary control. In July 2013 the Northern Ireland Electronic Care Record (NIECR), a digital care record that brings together key information from patients’ health and social care records throughout Northern Ireland in a single, secure computer system, was introduced.

With digital care records in place there are growing examples of where effectively linked data sets are providing multidisciplinary teams of healthcare professionals with timely access to vital information. For example, as of October 2015 an interface has been created to enable NIECR to be populated with data through each of the five Trusts’ diabetes information management systems.

“Having this data automatically transmitted to the centralised record is driving significant improvements for the delivery of patient care across the whole of Northern Ireland; it means consultants, doctors, nurses, social workers and GPs can be assured that treatment protocols are being followed in an appropriate and timely fashion, facilitating shared decision making and accelerating the most appropriate intervention where necessary.” Gary Loughran, eHealth Programme Manager, from the HSC’s Business Services Organisation (BSO ITS) (speaking to Health IT Central, March 2016).
Health and social care services are facing an unprecedented resource pressure, coming from growing demand as we live longer with more long-term conditions requiring support, coupled with shrinking public sector funding.

NHS England predicts that, if spending remains constant in real terms and service demands continue to grow at current rates, the NHS will have a funding gap of £30b per year by 2021. Despite the £4b recently announced for digital transformation of the NHS, and modest (just £25m) additional money for social care in the last budget, this gap will continue to grow unless action is taken and this includes drawing resources together with a different set of boundaries.

Plans to create a single, new organisation to deliver most adult health and social care services in Salford were approved by Salford City Council in May 2016. The Integrated Care Organisation (ICO) is set to launch in July with a budget of £213m, and will cover more than 2,000 staff working across adult community, mental and acute health and social care services. The ICO is expected to deliver £36m of recurrent savings by 2021, largely by reducing hospital admissions, cutting management costs and removing duplication.

Sharing resources across services makes sense, but one of the key challenges of combining health and social care provision is the need to unlock funding from a range of separated and entrenched budgets set in funding regimes which deter sharing or targeting investment more on prevention and community based care services.

A recent National Audit Office report (May 2016) looking at the problems of discharging older patients from hospital, estimated the cost to the NHS of older patients in hospital beds but no longer in need of hospital treatment is £820m. If these people were being cared for by social care or community services it would cost an additional £180m per annum. That's a net cost saving of £640m! Worse still, older people do not generally want to stay in hospital either.

NHS budgets are also often based on ‘throughput’ (volume delivered), which can be a disincentive to pool budgets which effectively reduce throughput. Annual budget-setting cycles also reduce the ability for essential longer-term planning of resources. Financial systems for care need to create greater scope for local decision-making with fewer hurdles to overcome, yet greater transparency about what is being spent and the value to the service user delivered.

The Department of Health estimates that it costs £400 per day to stay in hospital. A paralysed mother, Lucy Lowe, from Devon, became a ‘prisoner’ in a hospital bed for almost 2 years according to the press, after being refused a £30,000 grant to adapt her home. This stay cost the NHS more than £250,000, nearly 10 times the social care cost of home adaptions. She finally went back to her home thanks to public donations following an online campaign.
There are other benefits to pooling budgets beyond economies of scale. A more holistic approach to care budgets in an area and around a service user’s needs can help to monitor and manage demand levels, encourage greater self-service, and target specialist care more precisely to increase the productivity of a care professional’s time. But resource planning needs to cover all services relevant to the often complex care requirements of service users, so that packages of care can be optimised and resources ring-fenced to individual needs. Currently fragmented budgets result in decisions that are often point solutions for specific services or conditions and fail to manage the movement between care services adequately.

A broader approach to resource allocation can help to shift care away from hospitals and into community provision where appropriate. But it will require investment in those community services, moving budgets from the acute end of services, which will be unpopular. Simply investing more in primary and secondary care may in reality exacerbate the problem of integration.

Suppliers also find it frustrating that procurement of digital solutions is frequently implemented around narrowly defined budgets, losing the value of cross-sector systems. Many offer solutions that could readily be shared across health and social care, such as information tools and IT infrastructure, but have to respond to narrowly defined tender specifications. According to a recent FOI (freedom of information) investigation, fewer than one in 10 NHS Trusts even record spend with IT suppliers for example, perhaps because a variety of national organisations commission IT, so it is hard to track value. Suppliers often say that dealing with the NHS and social care is not easy – slow, expensive and failing to capitalise on the potential of new technologies to transform.
Recommendations

- Budgets should be pooled at a local level around the changing needs of the individual service user.
- Performance measures and funding should be based on models of desired outcomes not service throughput; incentivising joining-up of care services.
- Shifting care out of primary and secondary care and into the community will reduce pressure on services, but must be accompanied by investment in those community services.

Greater Manchester has this year taken control of a £6b NHS and social care budget. They still face a £2b budget gap, but expect to be able to use new powers to drive more efficient and productive services, as well as reducing cost pressures. Manchester CCG and Manchester City Council now share summary GP records, social care records, integrated care plans for crises and end-of-life plans. Hospital trusts are involved, and systems and data sharing are central to a single strategic plan.

In the past we have tried to manage the complexity of health and social care integration though a single grand plan – for example, NHS IT, ‘Connecting for Health’. These were not ultimately successful. But a single approach to joining up budgets and resources, at a local level, around the individual is needed. When linked to a national policy and national standards, this will strike the right balance of centrally based and locally based resources.
Conclusions

The real challenge in delivering a truly integrated and connected health and social care service, is to see the problem from the point of view of the service user – their location and their whole (and changing) needs. This is particularly true with long term conditions in older people. It requires a rethink of current models of professional silos, funding, governance, culture, language, processes, systems and data handling. It is not, primarily, about the technology (although digital models will be key) and it is not easy.

Service users increasingly expect to be able to:

● See all related care and support services in their area, not just NHS and Social Services.

● Access their care records and to correct errors or to add data (with controls).

● Track progress through the health and social care system.

● Share their data beyond health and social care professions with other related services.

● Book appointments which run on time and see test results quickly, using modern IT.

● Communicate electronically with care staff, without necessarily having to visit.

● Enter basic data once only, with simple validation during a course of care.

● Be confident in how personal data is handled and shared, including who can see data.

Progress is being made with electronic prescribing, the e-Referral system, ‘Patient on Line’ and streamlined electronic social care records and equipment services. But many case studies are isolated and need common standards to allow others to follow. Continued reliance on paper records slows down transformation, decision-making and service delivery, and increases risk of mistakes being made through human error or oversight.

A move to digital health and social care services should not only be designed in ways to make it more efficient, but also more accessible, more secure, more tailored to individual needs and more equitable. It should not disenfranchise or depersonalise and it should allow linkages across related services outside the traditional health and social care professions.

A ‘whole system’ approach to place-based delivery will dismantle a culture of professional silos resisting integration beyond a reluctant collaboration. But this depends on integrated governance and the pooling of resources through joint service commissioning. Devolution is to be welcomed, but has to genuinely move resources, autonomy and delivery to a much more local focus.

NHS England, NHS Improvement, the Care Quality Commission, Public Health England, Health Education England and NICE have come together to publish shared planning guidance to help local organisations to deliver sustainable health and care services building on the NHS plan ‘Five Year Forward View (5YFV)’ based around the new models of care. Under this planning, every local UK health and care area in England is asked to create a local, multi-year ‘Sustainability and Transformation Plan’ (STP) to accelerate the implementation of the 5YFV.

Yet whilst every CCG is expected to have created a local ‘digital roadmap’ in 2016, it remains highly questionable whether the NHS is going to achieve the target set by government of being wholly digital by 2020, let alone a new, whole system, place-based approach to care provision with the service user at the centre and in control.
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