

Addressing collective action dilemmas in the sharing of personal health data: Goldilocks and the installed base

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Abstract. Shared information infrastructures are required for personal health data to be shared along patient trajectories. Building such data sharing infrastructures will involve multiple stakeholders, which can be expected to share some common goals, but also to have divergent interests and priorities. Thus, collective action dilemmas easily emerge and may prevent progress. In the paper we wish to investigate how social structures influence the emergence (or avoidance) of collective action dilemmas. We have conducted a retrospective, qualitative analysis of the establishment of the Great North Care Record in the UK, focusing on the approach to mobilize and organize the participants. We find that pre-existing, multi-organisational peer networks, forums and relationships were in place and were actively used as social modules for mobilization. These networks and forums allowed spaces and occasions for interactions, observations and negotiations that were necessary to avoid and resolve collective action dilemmas. Thus, these networks and forums provided a core “social installed base” on which to build. These networks had been ‘organically’ emerging along the patient flow patterns. They followed the “Goldilocks principle” (‘just right’) – small enough to allow the avoidance or resolution of collective action dilemmas, and large enough that benefits would accrue from the cooperation.

Introduction

Sharing of personal health data between primary and specialist healthcare is required for safe care. However, many projects have experienced failures when organizing initiatives to establish shared care records, including the United Kingdom with its National Programme for IT (Currie, 2012; Justinia, 2017) and Denmark with its “Basic Structure of EPR” (BEPR) project (Aanestad and Jensen, 2011).

One of the explanations for the frequent failures is the size for such projects. Literature on large-scale projects finds that they are disproportionately prone to failures (Ansar et al, 2017, Flyvbjerg, 2017). A large project is more difficult to handle than a smaller one, and in particular it is challenging to ensure that the division of labour and coordination of work is optimal. In large projects it is exceedingly difficult to be able to detect and handle the interdependencies across several parts of the project, such as sub-projects that make decisions that impact other sub-projects (Bygstad and Hanseth, 2016, 2018). It is also more challenging to handle uncertainty and changes (Little, 2005). To reduce these kinds of risks, agile approaches are increasingly employed, also on large-scale projects. (Dingsøyr et al., 2019).

A second explanation of failures is the extraordinary socio-technical complexity of health and care work. Someone’s “constellation of care” (Wilson et al, 2017) means they may be using the services of a number of different care professionals working in separate departments in a range of organisations, each curating a separate part of the individual’s overall care record (Berg, 1999). Thus, challenges are also encountered when implementing information systems such as electronic patient record systems (Hertzum and Ellingsen, 2019). To reduce the risk for failures, participation of end-users is seen as a key factor for the successful procurement and implementation processes (Iivanainen et al., 2018; Wilson et al, 2017; Jenkins & Wilson, 2007)

Thirdly, healthcare organisations are not constants. The nature of public sector funding and the impact of changing policy is reflected in intermittent attempts to achieve improved patient outcomes via the vehicle of organizational change (Allcock et al, 2015). Mergers and splits occur and during the course of a project. However, although job titles and employers may change, often staff and roles in health IT remain the same. The “social installed base” can mitigate the risks of organisational churn.

There is also a fourth source of complexity stemming from the distributed and shared nature of integrated information infrastructures. Establishing such shared infrastructures require the mobilization and coordination of a set of actors (individuals, groups, and organizations), and while we may expect that they do share some common goals, there are also divergent interests and priorities among them. Therefore such initiatives are prone to so-called *collective action dilemmas*.

We have conducted an empirical study to answer the following research question: *How does the social installed base affect the scale at which a successful shared care record can be developed?* After presenting relevant theoretical perspectives on collective action dilemmas and collaboration, we will present a retrospective analysis of the successful establishment of the Great North Care Record in the UK, followed by an analysis of the approach to mobilize and organize the participants during the project, empirically illuminating the existence of a “social installed base”.

Related research on collective action and collaboration

How can heterogeneous actors be convinced to provide the necessary resources for the common good? Actors may hesitate to participate, as it introduces a risk that the other parties may not reciprocate and provide their share of the resource. Such situations, where what is collectively rational diverge from what is individually rational, are called collective action dilemmas (Olson, 1965; Sandler, 2015).

Communities of practice, professional networks and forums are adaptable models for multi-organisational collaboration which can support knowledge exchange, collective learning and the adoption of shared identity (Wenger 1999, Kislov et al 2011, Wilson & Lowe, 2018). Networks are “...cooperative structures where an interconnected group, or system, coalesce around shared purpose, and where members act as peers on the basis of reciprocity and exchange, based on trust, respect and mutuality.” (Randall, 2013). Ferlie and Pettigrew (2005) describe networks as a form of organising which is an alternative to hierarchies and markets. Inter-organisational networks are a feature of professional life and exist across the spectrum of informal journal clubs through to strategic exchange forums to collective decision-making structures (Health Education England, 2020). The effectiveness of collaborative structures is dependent on a range of factors including the negotiation of purpose (Eden and Huxham, 2001), existence of trust (Six et al, 2006) and achieving a critical mass (The Health Foundation, 2014).

Integrated care requires collaboration and communication at a micro, meso and macro level - at the point of direct care (micro), between organisations (meso) as well as legal and policy frameworks (macro). On a regional footing, there are long-standing formal and informal networks in healthcare. Most recently, integrated care systems (ICSs) have been established by the UK government to promote collaborative working and ‘remove much of the transactional bureaucracy that has made sensible decision-making harder’ (DHSC, 2021): ICSs operate on a regional basis, clustering organisations in a geographical footprint.

Research approach and case background

The Great North Care Record (GNCR) is an integrated care record project for the 11 NHS Hospital Trusts, 2 Mental Health Trusts, 370 General Practices, 1

Ambulance Trust, 70,000 staff and 3.6 million people living across the North East and North Cumbria (NENC) in England. We have conducted a retrospective qualitative analysis of the evolution of the GNCR programme from 2015 until 2020, the time period from the initiation of the Connected Health Cities (CHC) programme to the point of the GNCR shared care record go-live utilizing a common health information exchange for the region. The GNCR is a collaboration of NHS organizations, local authorities and universities and is now governed by the newly formed NENC Integrated Care System (ICS) Management Group, which is made up of Chief Executives of NHS hospitals, primary care and local authorities.

Data collection

Two of this paper's authors have been centrally involved in the establishment of the GNCR. Over a period of several years they worked with the GNCR programme: Professor Joe McDonald is an experienced clinical information: he was Chief Clinical Information Officer (CCIO) for a large Mental Health NHS Foundation Trust in the North of England when he joined the CHC and GNCR programmes as Director with overall strategic leadership responsibility. He was previously involved in the huge National Programme for IT (NPfIT). Louise Wilson was engagement lead at GNCR for three years: she has thirty years' informatics experience, convening national and regional networks.

Through this involvement they have access to wealth of information and insights about the evolution process and strategies employed, both documented and undocumented. To facilitate re-interpretation, as well as to control for insider bias the authors were interviewed by a third author, Professor Margunn Aanestad. In addition, three key written project documents were considered: Great North Care Record Vision (2016), Great North Care Record Technical Vision (2017) and Amy's Page (Wilson et al, 2020).

Data analysis

The analysis started by mapping the basic events of the evolution on a chronological timeline. Then we zoomed in on the challenges that related to the recruitment and onboarding of participants, where the collective action dilemmas would emerge, supported by deductive framework analysis of key published GNCR strategy documents. In the next section we present our analysis focussing on the strategy used in GNCR to co-develop infrastructure through active engagement with regional stakeholders.

The GNCR initiative

History and background of GNCR

This shared information infrastructure was a result of the North East and North Cumbria (NENC) component of the Northern England CHC three year pilot project (Shah et al, 2019, Steels et al, 2020) which began in 2015/6: the pilot operated on a geography dictated by the regional the Academic Health Science Network whence flowed the funding. CHC was intended to support multi-sector collaborations to test the idea of a Learning Health System (Friedman 2010, Foley & Fairmichael 2015) through partnerships across the NHS, academia, local authorities, patient organisations, suppliers and others. Four million UKP was allocated in 2015/16 by the UK government, to be spent over three years with no ongoing revenue to maintain the project.

The NENC response to the challenge of realising a Learning Health System was a three module approach to technology, informed by the work of Margunn Aanestad (2011, 2017). The three intended modules were:

1. Shared access to relevant health and care records
2. A platform to give the patients access to their information
3. A Trusted Research Environment (TRE)

The landscape of electronic patient record (EPR) systems in the North East and North Cumbria was described as a “perfect storm” in that all the hospital systems were from different providers and primary care systems evenly split between a *de facto* duopoly of suppliers. The GNCR approach was to connect existing health IT systems in the region, building on previous investments in technology. No partners were faced with a wholesale change of IT system with the cost and disruption that would create. The project would be built on the installed technical base.

With the relatively small and non-recurring funding and the commitment to a modular and cultivational approach, developing the regional shared record was prioritised. Although three modules were envisaged, there was only sufficient funding at that time to deliver one of the modules to the standards required for a safe, secure, trusted shared care record. The strategy was to “do one thing” and work on additional modules when possible. It was hoped that successful delivery of the first module would provide a foundation for future additions.

Delivering quick results and clear value early (Greenway et al, 2018) was critical so the shared care record development was prioritised, building on the achievements of implementing two existing and proven technologies that had begun deployment as part of a regional Urgent and Emergency care transformation programme (Maniatopoulos et al, 2017) - the Information Sharing Gateway (ISG) and the Medical Interoperability Gateway (MIG). These tools had allowed secondary care staff a one-way view of an attending patient’s primary care record with one button click from within in the context of the secondary care electronic patient record (EPR): hospital clinicians had a richer picture of the healthcare

record than they had previously had (GNCR, 2020), and the reputation for quality that the primary care record had was an important component in trusting the data they could see. The direct beneficiaries of this new way of working were those specialist healthcare practitioners as well as the patients and service users themselves. GPs also reportedly benefitted from fewer phone calls from other care delivery organisations seeking additional information.

Usage figures rose exponentially. By 2017, the technology and information governance (IG) arrangements were aligned and all 370 GP practices in the NENC region were sharing records with the 12 local hospital Trusts, 2 Mental Health Trusts and the regional Ambulance Trust. This first phase established the cultural foundations of trusted information sharing for direct care.

So having solved one collective action dilemma by all agreeing to deploy MIG in all organisations, the region faced a new collective action dilemma in evolving the full shared care record. By 2017, Health Information Exchanges (HIE) offered a natural evolution because they enabled two way viewing of health records for direct care by permitted practitioners. But within the NENC region, the leaders of three sub-localities proposed an HIE each but stakeholders were convinced by the logic to have only one. But which one? The dilemma was solved by engaging key partners in co-producing an evaluation criteria and selection process which then resulted in a shared selection and agreement on a single HIE. In doing so, strategic cooperation and a more formal governance structure was evolving.

A critical factor in driving that progress was a loose coalition of IT and health professionals that had formed, a kernel of like-minded people who had worked together on other projects as far back as the 1990s. Some had formed social friendships as a result, and found a new common goal in improved data sharing between organisations to improve direct patient care.

This coalition shared knowledge and found informal agreement on the best data sharing approach for the region which they then championed in other spaces, including more established networks, regional governance boards and within their own organisations. The coalition achieved a major leap forward in information sharing and in doing so became a team capable of coming together to deliver other modules of the increasingly shared vision, "...the only way to learn how to do this stuff - is to do this stuff".

With no formal authority to compel organisations to join the programme and with the continuous organisational churn in the NHS, progress was again made possible by the longstanding personal relationships of the participating actors. Trust was at the heart of the project: there are limits to the number of people actors can 'know *and* trust' and this limits the size of what is possible. Too small and the absence of economies of scale render the project too expensive, too big and the diameter of trust (Ainsworth & Buchan, 2015) is breached and information sharing with people you don't know overwhelms the confidence of the information governance community.

The role of groups: the “Social Installed Base”

Central funding of regional NHS information technology (IT) projects tends to be *staccato* in nature. This financial instability, combined with the instability of continuous “churn” of NHS organisations is contrasted by the constancy of the people working in the NHS IT field: employers and job titles change but the “faces around the table” at regional NHS IT meetings don’t change as frequently.

From the start, the GNCR core team took a modular approach to building the social infrastructure for the project using existing groups across the region to build a “team of teams”. The GNCR *Vision* (2016) described a modular, cultivational engagement approach not just of starting with a defined but diverse coalition partnership then adding in sectors, organisations, professions - as implementation progressed. For example, teams of Chief Executives, Finance Directors, CIOs, IG leads, social care leads and local informatics boards that were already in place with terms of reference and decision-making mechanisms.

However, there were gaps so two new groups were set up: a GNCR membership network, offering an on-line discussion platform and in-person events, was launched in 2017, and the GNCR Professional Advisory Group made up of CCIOs was set up in 2018. The strong GNCR brand, dedicated benefits-led communications and focus on working with existing channels contributed to the rapid establishment of both groups. Taking this approach, different cohorts were able to advance at their own pace. A modular approach also invited a sustainable ‘growth road map’ that a ‘big bang’ approach did not - new professional groups or sectors would be added as needed by engaging with whatever regional peer network that cohort had established already.

The Goldilocks myth? Not too big, not too small

The larger the number of partners involved, the more complicated the calculations become that participants make when faced with a collective action dilemma - calculations of trust, reciprocity, losses and gains and risk. Conversely, “...if the size of the group is reduced, the potential difficulties of organizing collective action are correspondingly decreased.” (Olson 1965 cited in Heckathorn 1996).

Unlike the churn associated with public sector restructuring, regional decision-making boards and networks are usually not set up and disbanded on a project-by-project basis but cover multiple topics of common interest.

Regional collaborative networks in Northern England have historically been influenced by ‘natural patient flows’ and administrative regions which in turn have been informed by other factors affecting human movement, specifically natural features like rivers and mountains and travel infrastructures - roads and railways. These leave a legacy influencing how regional collaborations operate.

An assumption underpinning the GNCR programme was that these established collaborations had already done the work of forming, storming, norming and

performing (Tuckman, 1965) and were familiar with making the calculations associated with collective action dilemmas for other initiatives encountered before GNCR. A meso-level ‘social installed base’ was in place. Thus, the GNCR engagement approach became to work out how to attach GNCR to their agenda rather than enrol them to the GNCR one - be adopted rather than adopt. This had the additional advantage of not placing further demands on busy people’s schedules for new, project-specific meetings.

For GNCR, this meant the size and scale of the shared care record project was driven by pre-existing relationships and the number of members belonging to existing networks rather than a calculation based on a notional “ideal” number of partners, organisations or patients: the social installed base defined the project size and scale.

Acting collectively to overcome dilemmas

In the GNCR programme, voluntary cooperation – where actors choose freely whether to cooperate or not (Heckathorn, 1996) - was the only option available because at the time there was no regional strategic authority (possibly now remedied by the development of the ICS) and there was insufficient funding to incentivize organisations, beyond the benefits of time saved and safer care delivered. The ‘social norm’ of patient-centredness (NHS England, 2014) invited the voluntary cooperation of senior decision-makers. The articulation of the need for improved information sharing was not new, but GNCR offered the means to achieve it collectively and build incrementally to a grander regional scale.

In the North East and North Cumbria, the spaces and occasions for key members to observe each other, be informed about the others’ opinions, judgments, choices and undertake joint deliberations were well established in the form of regional collaborative forums. These forums became the place for GNCR-specific joint deliberations and negotiations - such as senior IT leaders agreeing criteria for technical specifications - which paved the way for common action.

In terms of monetary rewards, the CHC funding to the North East and North Cumbria provided a financial authority that legitimised the discussion followed. The CHC funding was secured by the established AHSN in NENC which in turn mapped broadly to a number of parallel forums and networks, the ‘team of teams’.

In the context of the GNCR, a consistent and compelling case relating to the benefits to patient care, improved outcomes and spending less on postage stamps was aligned with a well-communicated brand which also appealed to regional identity. Heckathorn noted Fireman and Gamson's (1979) argument “that potential social dilemmas in collective action are resolved through appeals to identity and building group solidarity.”

The principles of informed consent and public engagement which the GNCR operationalised also speak to the idea of seeking voluntary cooperation from the

public. A series of NENC Healthwatch-led public focus groups, participation in regional Citizens' Juries (Connected Health Cities, 2017), media communications, a patient-facing website and enquiry telephone line were all designed into the GNCR programme.

Concluding remarks

The Great North Care Record is an initiative to improve health and care record sharing in the North East and North Cumbria with the express aim of improving care and outcomes: the shared care record is one element which saw the successful implementation of an interoperable health information exchange, connecting a technical installed base of disparate NHS and local authority IT computer systems operating within different health and care provider organisations.

From GNCR's inception, 'team of teams' - a social installed base of existing networks, forums and relationships - worked together to overcome a series of collective action dilemmas in order to realise the benefits would accrue from a shared care record. The footprint of the social installed base drove the size and scale of the project, and was arguably critical in informing the calculations that individuals made when facing dilemmas about if and how to proceed collectively.

Cultivating technical modularity (Aanestad et al., 2017) in the GNCR programme afforded advantages of incrementally building on digital infrastructure that was already in place. In parallel, working with the social installed base and cultivating social modularity afforded advantages of incrementally building on established human infrastructure. While much of the Information Infrastructure literature has prioritised attention to technology and architectural forms over the social aspects, the recognition that an information infrastructure involves a network of people has also always been central and is a domain for further exploration.

The commonality of language between the documented features of health and care networks and the features of collective action dilemmas - trust, reciprocity, shared purpose, gains, losses - invites further exploration to understand more about how working with established groups can enable collective approaches to digital transformation.

Whether this cultivational, modular approach to both professional engagement and technical implementation could be deployed in another region would depend on the maturity of its collaborations - how to connect the connected is also a question for further study.

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