Case Study A

1. A - Introduction

A study investigating antimicrobial resistance seeking prescribing information from GP practices to assess the quality of treatment decisions for patients with acute bacterial infections.

2. A - Scoping and landscaping

We started with a focus on the problem: rising antibiotic resistance and the problem of overprescribing, often by GPs. We arranged an event to pull together key stakeholders regarding quality prescribing in general practice. At this event, stakeholders pulled ideas for what they would want in a data-driven tool to inform them about how to make improvements.

The researchers had experience using GP data available nationally. This preliminary analysis informed the specification of data sought from local providers. Data were sought from the new local integrated care record as this would include data from general practice and from patients admitted to hospital experiencing complications from antibiotic resistance.

3. A - Approvals

Although the local integrated care record had planned to make linked data available for research, the systems were not in place in time for our project. We decided instead to drop the hospital element and just get data directly from pilot practices. This involved getting Health Research Authority (HRA) approval to conduct the research study with a particular IT provider who could extract data from participating GP practice computer systems. The data would be sent to the university for analysis by the project analysts. The university signed a contract with this IT company. To participate practices needed to have their Caldicott Guardian sign an agreement with the university and another with the IT company.

4. A - Project planning

From the initial draft of an application form, HRA approval took 7 months. Agreements with the IT provider were drawn up after this in the spring and needed a minor amendment (changing from the integrated record). The system to process the data took a further 6 months to build, with added time for checking and approving the data request (meeting the data specification proved more tricky than initially envisaged). From drafting the initial data specification to showing the analytical tool to participating practices took over 18 months.

The delays in getting permissions and especially in building the infrastructure meant that recruitment of practices needed to stop. There was also only a 2 month window to deliver the solution to practices that had already signed up.

Case Study B

1. B - Introduction

A study into a chronic respiratory disease (COPD) investigating pathways of inpatients and outpatients across a conurbation.

2. B - Scoping and landscaping

A planning meeting was held between an existing member of the project and a new manager, which identified NHS Digital as the main source of data across various healthcare providers in the region. The application form was completed and went via the Data Services for Commissioners Regional Office (DSCRO), which is a local office that deals with NHS Digital data.

3. B - Approvals

The application underwent a two-step approvals process, and in between we had a face to face meeting with a representative of NHS Digital. They required payment of a five-figure sum. There were some delays in getting the data. Initially we were told the data would flow within 24 hours of board approval but in the end it took over 3 months, and in the meantime we amended our request to cover a slightly larger geographical footprint and to extend the time that we could access the data.

4. B - Project planning

It took 7 months from initial, serious enquiry with NHS Digital to receiving data from them. In this timeframe new data protection regulations (the GDPR) came into force which resulted in additional queries that came up regarding the status of different organisations some of which needed to renew their data controller registration with the Information Commissioner’s Office (ICO).

Case Study C

1. C - Introduction

A study aiming to make more health information about vulnerable families available to social workers.

2. C - Scoping and landscaping

Our project aimed to share data among multidisciplinary Early Help social care teams to support the care they offer to families. The project team is made up of university health services researchers and the technical team at the university and a local company. There was also a qualitative researcher who interviewed families and practitioners who are involved with Early Help services about their experiences of information sharing.

We participated in a steering group across five local authorities, project members, and some other researchers. Liaison was needed with a litigation manager, an information rights officer, clinical safety officers, and care professionals. The steering group determined that a new Interoperability system would supply data, and that the project would be hosted securely at a private IT company.

3. C - Approvals

The qualitative researcher needed university research ethics committee approval before seeking interviewees. The project team needed to build the system to comply with clinical safety requirements. Information sharing agreements needed to be in place for each participating care provider and with each Local Authority. Once the agreements were signed there was a 6-8 week timeframe before data were received.

4. C - Project planning

Project management was led by a health informatics service team. Building a network of enthusiastic stakeholders and getting signed agreements has been time consuming. Following delays we had to focus on the data flowing to one local care team as a proof of concept involving just one local GP practice as a service improvement pilot.

At the start of the project we were aware that information governance would be time consuming. One member of the project left early, and another went on parental leave. Remaining members of the project team has goodwill but no specialist experience in information governance, and the new data protection legislation (the GDPR) posed uncertainty. In hindsight it would have been beneficial to have had more representatives from across health and social care involved in the steering group.

Case Study D

1. D - Introduction

A study aiming to understand complex health problems in the very elderly population across one city using statistical modelling.

2. D - Scoping and landscaping

We started with a focus on the problem: Population modelling work investigating frailty and multimorbidity to improve health and wellbeing of a city's population. We sought linked, pseudonymised data including primary, secondary, and adult social care data for the city.

3. D - Approvals

We needed to ensure registrations and approvals were in place with the Information Commissione''s Office, local medical committee, senior stakeholders (including Caldicott Guardians) within Trusts and Local Authorities, the Clinical Commissioning Group (CCG) forum, and regional Commissioning Support Unit (CSU).

Paperwork we needed to complete included Data Protection Impact Assessments (DPIAs), and data sharing agreements with each data provider.

4. D - Project planning

It took six months to get HRA approval to approach GP practices, then to sign agreements with 88 GPs, 3 trusts and one local authority.

Once approvals were in place we needed to deal with technicalities of extracting data from organisations, for example the CSU provided 'SUS' data about users of secondary care. Some of this involved special "black box" software from a company that could extract data from GP systems. The networking and firewalls also needed arranging with BT. This all took 18 months from agreements being signed to getting data from primary care. During this time period we worked on pilot projects with some GP sites to try to get things moving.