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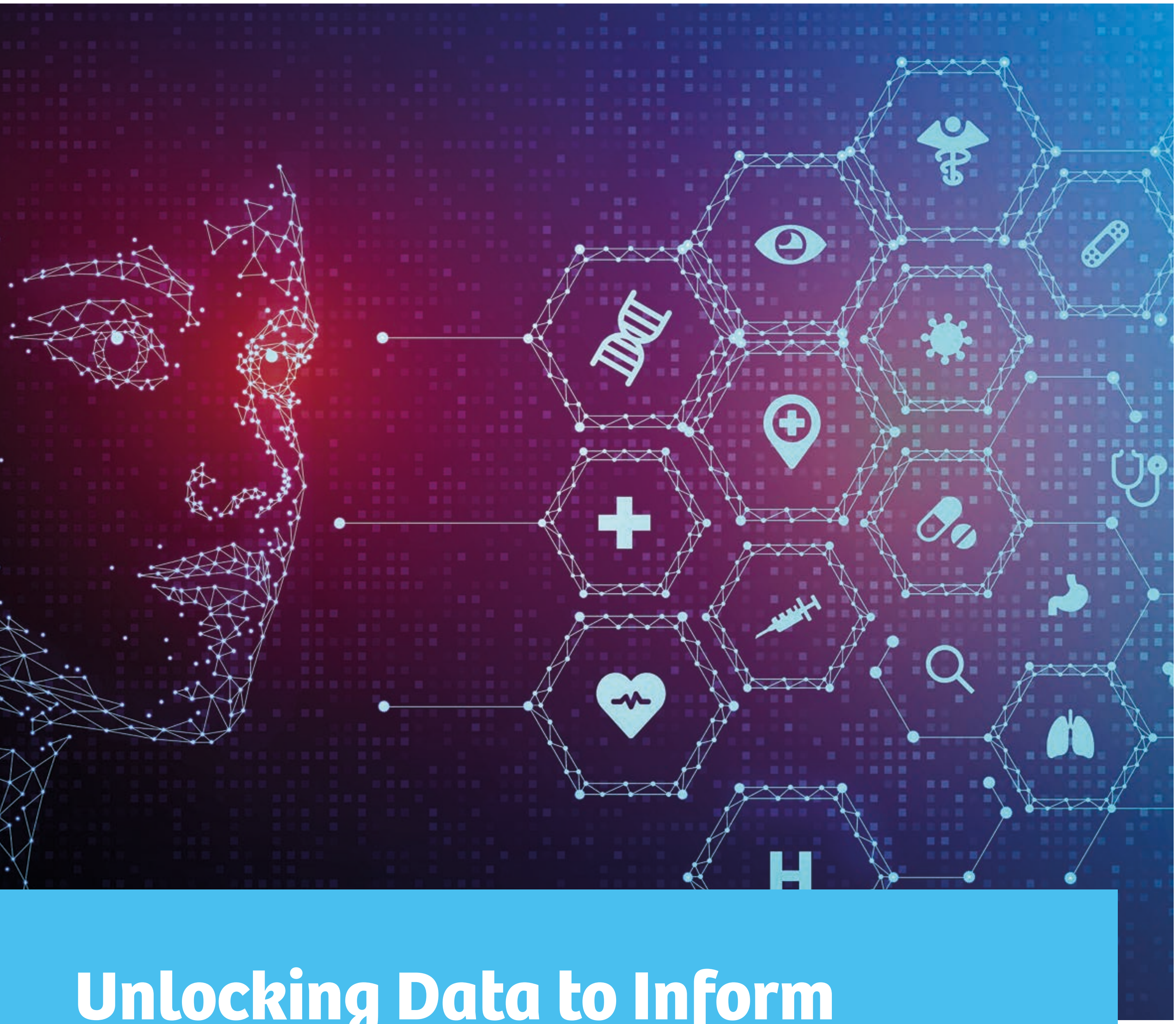

Unlocking Data to Inform Public Health Policy and Practice

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Unlocking Data to Inform Public Health Policy and Practice

Matthew Franklin (MF)1*, Tony Stone (TS)1, Susan Baxter (SB)1, Annette Haywood (AH)[1], Sebastian Hinde (SH)[2], Daniel Howdon (DH)[3], Monica Jones (MJ)[4], Anthea Sutton (AS)[1], Mark Clowes (MC)[1], Suzanne Mason (SM)[1], James Lomas (JL)[5], Louise Brewins (LB)[6], Philip Truby (PT)[7], Michelle Horspool (MH)[8], Kamil Sterniczuk (KS)[9], Jennifer Saunders (JS)[7], Christopher Gibbons (CG)[6]

* Principal Investigator; please send correspondence to: matt.franklin@sheffield.ac.uk

[1] School of Health Related Research (ScHARR), University of Sheffield, Sheffield, England, UK.

[2] Centre for Health Economics (CHE), University of York, York, England, UK.

[3] Academic Unit of Health Economics (AUHE), University of Leeds, Leeds, England, UK.

[4] Professional Services, University of Leeds, Leeds, England, UK.

[5] Department of Economics and Related Studies, University of York, York, England, UK.

[6] Sheffield City Council, Sheffield, England, UK.

[7] City of York Council, Sheffield, England, UK.

[8] Sheffield NHS Clinical Commissioning Group (CCG), Sheffield, England, UK.

[9] Patient and Public Involvement (PPI) co-applicant, UK.

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CONTENTS

A1. EXECUTIVE SCIENTIFIC SUMMARY

Context

If local authorities, clinical commissioning groups, and/or integrated care systems (ICSs) are to be full partners alongside researchers in the generation and use of evidence, then relevant data requirements, legal and information governance (IG), and evaluation frameworks must be geared towards local contexts and commissioning needs. By exploring these aspects, we produce policy and practice recommendations.

Work-packages (WPs)

Building on examples from the identified grey literature (WP1), we sought to develop a metadata specification and pilot metadata catalogue to help inform commissioning processes including via relevant legal and IG frameworks (WP2). The project combined qualitative methods via workshops to explore the availability and potential of routinely collected administrative and service activity data for secondary uses (WP3), with an exploration of quantitative methods to maximise data use to support evidence-based decision-making and its value to stakeholders and the public (WP4).

WP1: Mapping review

Eighty case studies were identified from 71 documents: 31 were included for data extraction focused on: (i) data sources; (ii) data 'controller' and 'processor'; (iii) enabling legal or IG frameworks; (iv) any difficulties; (v) data presentation. Missing data of interest was common. The goal of sharing and linking data was rarely explicit; reporting of realised public benefit was almost entirely absent.

WP2: Metadata

Staff involved in data management and analytics identified many benefits of metadata; however, we were not able to develop comprehensive metadata for adult social care. Barriers included poorly documented information systems and a lack of: existing metadata, senior-level recognition of metadata utility, and funded time/roles. Key legal and IG frameworks to enable data access, linkage, and sharing were identified. Unlocking and linking data requires good understanding of existing data, identification of legal gateways, demonstration of utility, senior-level buy-in, alongside public trust.

WP3: Workshops

Across 18 staff participants (nine workshops; five interviews) and 17 public members (two workshops), four themes were identified. (1) Context and timing such as the Health and Care Bill 2021 and pandemic-driven COPI notices were perceived as opportunities for unlocking data, but many remained pessimistic if change would happen/continue. (2) Need for a different approach including enhanced communication, co-operation, and strategic thinking about data use and sharing between commissioners, researchers, and the public. (3) Obstacles and enablers included 'governmental and legal' (e.g. organisation functions and IG aspects), 'organisational' (e.g. senior-level buy-in, capacity/ capability/ skill constraints), and 'process factors' (e.g. lack of interlinked data, use and understanding of data). (4) Challenges of communicating information to the public to strengthen understanding and trust in data for secondary uses.

WP4: Health economics

Researcher-led evaluation frameworks employing data do not always meet the needs and realities of local decision-makers; additionally, required data is not always known, available, or usable. There are various barriers to overcome to enable consistency across researcher-led and commissioner-led approaches; e.g. agreement on how aspects are quantified and outputs presented. There are barriers likely to be perpetual in the alignment of approaches, such as commissioners' requirement to place their legal duty at the heart of any commissioning decision, and the cost and skills for data analysis.

How to unlock data for policy and practice

In order to increase public understanding and buy-in, organisations should openly publish how data sharing and linkage has been used and any realised public benefit. There are legal and IG frameworks to permit responsible use of data; although, confusion and frustrations with current pathways exists. Without appropriate metadata, data discoverability and understanding are hurdles for maximising the value of data for external stakeholders. Collaborations across sectors and universities should broaden, relevant skillsets across disciplines and sectors should be funded to grow and merge, there should be increased linkage of datasets to maximise the value of collected data, accessed in a secure framework allowing analysis across research and commissioning questions for public benefit. Current researcher-led quantitative frameworks could be used to inform commissioning if there was more alignment in understanding and presenting relevant outputs, alongside funded job roles and skills.

A2. PLAIN ENGLISH SUMMARY

Background

In England, many services that are paid for using taxpayers' money are decided on and funded by local commissioners such as Local Authorities (LAs) and Clinical Commissioning Groups (CCGs); although, CCGs are set to be replaced by Integrated Care Systems (ICSs) within 2022. LAs are responsible for publicly funded social care (e.g. home-based services) and some public health services (e.g. sexual health services). CCGs are responsible for funding most healthcare services in local areas. All local decision makers aim to fund services for public benefit; for example, promoting and protecting health and preventing ill-health, while ensuring 'value for money' for taxpayers. Such services and local decision makers often collect data to inform their processes. This data is used to support the services provided for individuals, but also for administrative reasons. This data could be used more often to help inform improvements to current services and funding of new services, but also to support research by universities. However, as this data could include potentially personal and sensitive information, it is important that it is protected and only shared in circumstances when there is a clear and legal reason that would benefit the public.

What did we aim to achieve?

We set out to understand: (1) what data is available to local decision makers; (2) how they currently use it; (3) how data can be used and potentially shared with parties who want to use it for public benefit. Furthermore, we aimed to explain how to best use and share data legally with clear reasons for its use. An example would be helping local decision makers calculate which services are considered 'value for money' or not, to allow local decision makers to best use money available to them.

How did we do it?

We first identified examples of when data has been used and legally shared to inform local decision making. We then produced a detailed list of what data these local decision makers have available. These examples and data were discussed with people who work within two LAs and a CCG, within three universities, and members of the public. This allowed us to further explore what is important to consider when using such data to inform local decision making or research purposes, and how the use of such information could be made more transparent and understandable for the public.

Patient and the public involvement in the project.

A lay co-applicant (KS) helped with every aspect of the research project. We additionally set up a public advisory group to advise on the public workshops, interpretation of the findings, and co-design study outputs.

What did we discover?

Local commissioners are using and sharing data in various ways to benefit the public, such as identifying if certain people may be at-risk of a bad event; for example, older people at-risk of falling who would then require hospital and perhaps social care. However, local commissioners are not always clear in how they report the use of such data, who has control or is using such data, and if any public benefit was ever achieved from recording this data. We attempted to develop an understanding of what data was available for adult social care services. However, we were unable to achieve this aim because of issues to do with the amount of time, effort, and types of staff available within the relevant local commissioners to understand the data available. By discussing the need and use of data with LA and CCG staff, and members of the public, we identified a variety of areas to improve the responsible use of data. One thing discussed was the need for trust and understanding between everyone involved about how and when data is being used, what data is used (for example, if it reflects an individual or group), but also the public benefit of using such data. When analysing data, researchers and local commissioners need to communicate better and come to a joint understanding of how such data can be accessed and used for public benefit. This includes information about what services are considered value for money and who may be paying for what aspects associated with the services across CCGs and LAs, and if there is any chance spending may not remain within budget. Overall, there are ways to responsibly use data which protects the public and could provide public benefit such as treating or avoiding ill-health; however, clearer communication and building trust is needed.

How will this research change health and social care?

We believe our research could start to change and improve how researchers and local decision makers use locally available data to decide which services to fund to benefit communities. This includes suggested information to be made clearer to the public.

A3. RECOMMENDATIONS

Across four work-packages and in consultation with LA and CCG staff, and the public; we recommend:

1. **Reporting standards.** Minimum reporting standards for documents detailing use and linkage of data; e.g. the data being shared, with whom and for what purposes must be listed, including (when applicable) the legal and IG gateway for access to, or linkage of, data (WP1).

2. **Openly published documentation.** To increase public understanding and buy-in, organisations undertaking data sharing and linkage should openly publish how such sharing and linkage has been used and the realised public benefit, with both scientific and plain English summaries (WP1).

3. **Legal and IG frameworks.** Further clarification and simplification is required of legislation and governance around responsible cross-sector data sharing, potentially by incorporating health and care data within the Digital Economy Act 2017 (WP2).

4. **Metadata.** National and local support is required as to the utility and resource requirements of developing and maintaining metadata, including recognition and support at senior and executive levels. National government should invest in local authority information system infrastructure and associated staff roles (e.g. via the Levelling Up Fund), focussing on the adoption of data standards and modern data management practices; funding should be nationally sourced and locally ring-fenced, with clear job roles and titles to enable transparency and identification of such staff role members for those within and external to such organisations (WP2+3).

5. **Data sharing and linkage.** There is an opportunity to build on the processes and relationships developed during the COVID-19 pandemic, but there needs to be greater clarity in purposes for data sharing, and appreciation at senior levels of the potential utility/value of data sharing between health and local authorities (WP3).

6. **Secondary data use clarification.** New and clearer ways are needed to communicate the importance and nature of secondary data uses (e.g. commissioning and research purposes) to the public in order to build trust; this includes explicit statements of when data can be considered individual-level or not (e.g. aggregated), at what point any aggregation may occur (e.g. at service source), and making clear distinctions between public and charitable sector (e.g. local commissioners and university) and private sector uses (e.g. ‘private insurance companies’ are commonly mentioned) (WP3).

7. **Actions at multiple levels.** Actions to facilitate improved data sharing need to happen at a number of levels including governmental and legal, organisational, and data processing if current barriers are to be overcome; for example, by implementing our recommendations (WP3).

8. **Data and evaluation.** A common set of vocabulary around definitions of health inequality, and agreement on how aspects of health inequality are to be quantified e.g. through minimum data specifications (WP4).

9. **Broadening and strengthening collaborations.** The need to strengthen collaborations between researchers and commissioners to ensure better understanding of data systems, access and trust (WP4).

10. **Bridging the gaps.** Better reflection and documentation of where existing quantitative frameworks for determining cost-effectiveness do not incorporate challenges faced by local commissioners, e.g. finance and policy cycles, ring-fenced budgets, risk aversion to overspend, and diverse outcome measures (WP4).

A4. OVERVIEW OF CURRENT OUTPUTS AND DISSEMINATION

Online Blogs with hyperlinks

1. Unlocking real-world data to promote and protect health and prevent ill-health in the Yorkshire and Humber region – published via the Health Economics and Decision Science (HEDS) Blog
2. "It's A Grey Area": searching the grey literature on how local governments use real-world data – published via the HEDS Blog
3. Unlocking linked real-world data presents opportunities to improve public health – published via the London School of Economics (LSE) Impact Blog

NIHR Applied Research Collaboration Yorkshire & Humber (ARC-YH) Blogs with hyperlinks

1. Unlocking real-world data to inform public health policy and practice – an introduction to care metadata – NIHR ARC-YH short blog which links to our online webinar (1)
2. "It's A Grey Area": searching the grey literature on how local governments use real-world data – NIHR ARC-YH short blog which links to online blog (2)
3. Unlocking Data to Inform Public Health Policy and Practice – NIHR ARC-YH blog of our report's plain English summary

Online Webinar or Video with hyperlink

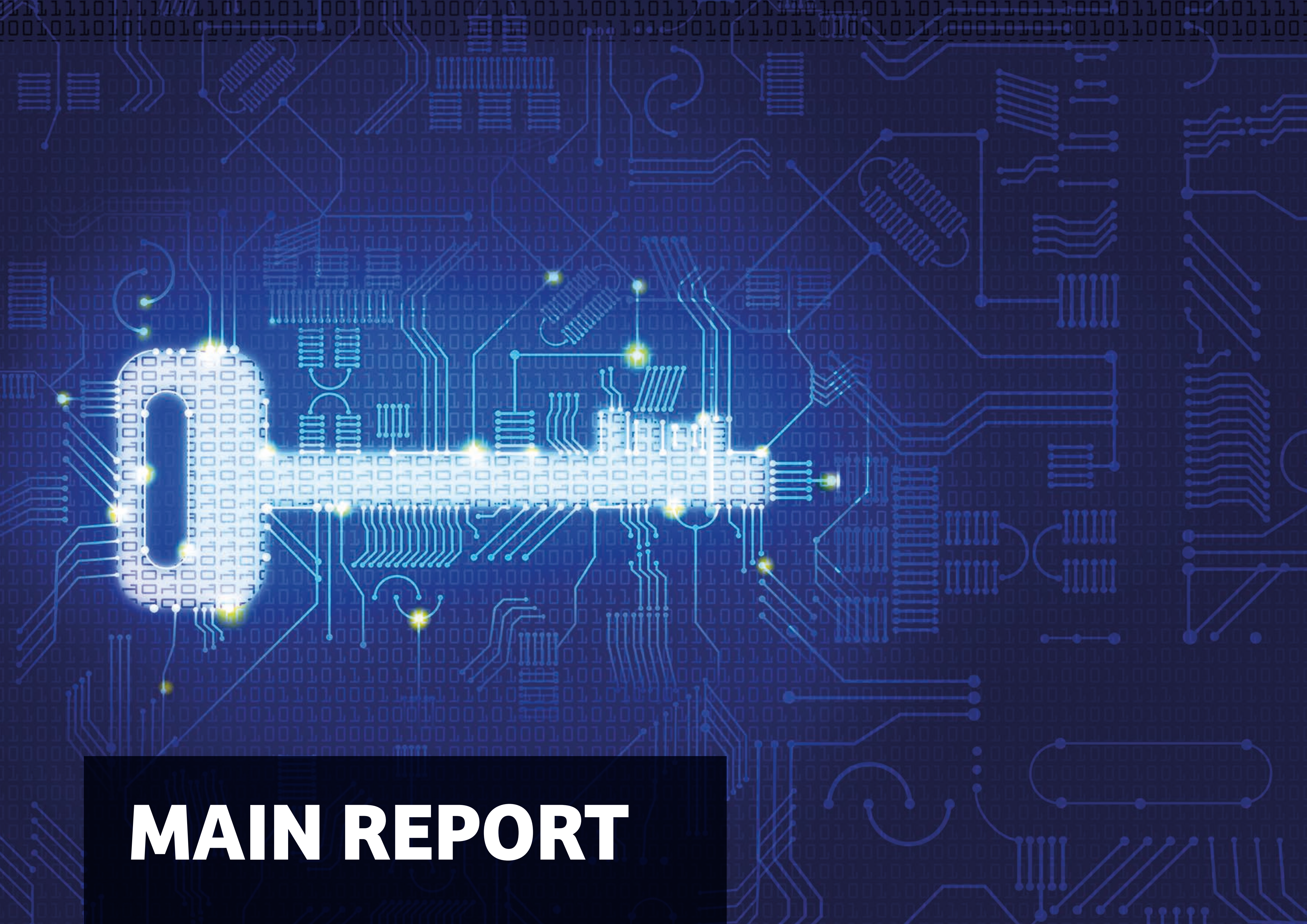
1. An introduction to care metadata – published via the HEDS Blog and NIHR ARC-YH website/newsletters
2. Understanding and Addressing Inequalities: Sebastian Hinde – HSR UK Conference presentation of peer-reviewed publication (1)

Online Podcast with hyperlink

1. Health inequalities: to what extent are decision-makers and economic evaluations on the same page? Greg Fell talks to Seb Hinde and Dr Matt Franklin – available on Spotify or The University of Sheffield Player – ScHARR's Communicable Research podcast, episode 11, of peer-reviewed paper (1)

Planned peer-reviewed publications

1. Health inequalities: to what extent are decision-makers and economic evaluations on the same page? An English case-study – published within *Applied Health Economics and Health Policy*
2. Economic evaluation evidence for resource-allocation decision making: bridging the gap for local decision makers using English case studies – published within *Applied Health Economics and Health Policy*
3. Navigating data governance associated with real-world data for public benefit: an overview and future considerations – submitted to *BMJ Open*
4. Sharing real-world data for public benefit: a qualitative exploration of stakeholder views and perceptions – submitted to *BMC Public Health*



MAIN REPORT

1. INTRODUCTION AND CONTEXT

Local Authorities (LAs) are responsible for commissioning publicly funded social care and some public health services [1]. Routinely collected administrative and service activity data is key in supporting LA decision-making, including yearly commissioning cycle stages (Figure 1) [2]. The Better Care Fund encourages LAs to work with Clinical Commissioning Groups (CCGs), who have statutory responsibility for commissioning most NHS services, by utilising joint working arrangements including integrated commissioning boards and pooled budgets [3]. The Health and Care Bill 2021 seeks to embed joint working, making integrated care systems (ICSs) statutory within 2022 [4].

Finite budgets available to achieve within and cross-sector strategic objectives requires evidence suggesting which services are affordable while providing cost-effective options for health improvement/promotion, preventing ill-health, and/or protecting health [5-7]. Although such considerations are built into some commissioning business cases, they focus mainly on costs (i.e. accounting processes) rather than opportunity costs (e.g. between relevant alternatives) alongside non-monetary outcomes (e.g. health gains, inequality impact). There's also restricted capacity and skills to share and analyse data such that inaccurate/incomplete information could be informing cross-sector commissioning decisions, resulting in unrealised future benefits, unrecoverable sunk costs, difficult disinvestment decisions, with subsequent public and political criticism.

Research can support commissioning processes; Prof Whitty (CMO) promotes co-production to avoid disconnect between academic research and commissioners' evidence needs [8]. For example:

1. Identifying **data requirement**s for informing the commissioning cycle, within and across sectors dependent on the commissioning scope and where short and long-term costs and outcomes may fall;
2. Accounting for **legal and information governance (IG) frameworks** alongside broader **barriers and facilitators** to access, use and sharing of data (e.g. staff skill and capacity, data systems);
3. Establishing **evaluation frameworks** to enable data to be used in transparent and useful ways aligned with commissioners' evidence needs.

Through consultation with representatives of the City of York and Sheffield City Councils, Sheffield CCG, and public members, we produce recommendations as how to 'unlock data' for policy and practice.

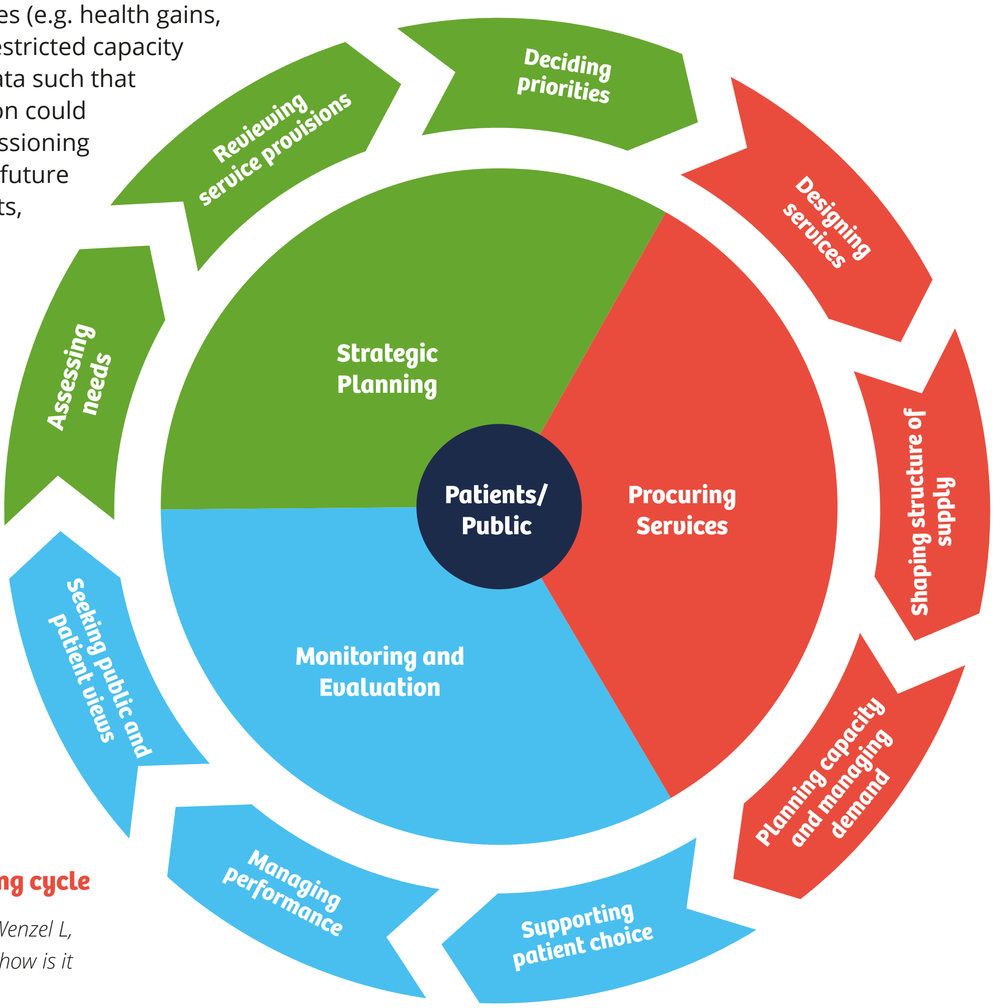


Figure 1: The yearly commissioning cycle

Image adapted from a similar figure by "Wenzel L, Robertson R. What is commissioning and how is it changing? 2019 04 August 2020]; Available from: https://www.kingsfund.org.uk/ publications/ what-commissioning-and-how-it-changing"

2. AIM, WORK-PACKAGES AND OBJECTIVES

Aim: to delineate the availability and potential of routinely collected administrative and service activity data to support commissioning decisions within and across sectors including LAs, CCGs/ICSs, and universities, in order to promote and protect health and prevent ill-health in local and regional settings.

Work-packages and objectives

WP1: *Mapping review of use and linkage of routine data in local/regional settings for commissioning decisions informed by LAs in England*

- Describe current availability, linkages, and use of routine data for the purpose of within or cross-sector commissioning informed by LAs in England.

WP2: *Metadata specification and pilot metadata catalogue through stakeholder consultation*

- Develop a metadata specification and pilot metadata catalogue;
- Develop guidance on legal and IG frameworks to link data and enable data flows;
- Describe how linked datasets across sectors can inform commissioning and research.

WP3: *Workshops with stakeholder groups to explore routine data requirements to inform commissioning*

- Identify key organisational, technical, legal and resource barriers to foster positive change to data sharing and linkage locally/regionally, including suggested solutions;
- Understand and describe public and stakeholder perceptions of data for secondary uses;
- Understand and describe how the COVID-19 pandemic may have been a change catalyst.

WP4: *Economic evaluation (EE) methods to analyse and present estimates from routine data to inform cross-sector commissioning*

- Explore how to maximise the use of data to facilitate cross-sector working across LAs and associated bodies such as NHS commissioners.
- Describe EE methods to improve public health and commissioning by accounting for: cross-sector outcomes and costs; health inequalities; affordability, budgeting, and cost-effectiveness.

3. METHODS

3.1. WP1: Mapping review

Our review focuses on grey literature (e.g. websites and bespoke structured reports), as use of routine data for commissioning purposes are seldom reported within peer-reviewed journals. As grey literature reporting sources and standards are variable, traditional systematic review approaches are not appropriate; instead, we chose a mapping review approach to: "map out and categorise existing literature from which to commission further reviews and/or primary research by identifying gaps" [9]. Here we identified case studies of interest to our study steering committee (SSC) and study meeting group (SMG) stakeholders, with reporting completeness or quality secondary considerations. Appendix S1 describes: source identification and search; study selection; data extraction; contacting project leads for missing data; SMG and SSC consultation.

3.2 WP2: Metadata

Through workshops (Section 3.3) and bespoke meetings with stakeholder representatives, we sought to develop a metadata specification and a pilot metadata catalogue listing data assets across stakeholders, with a focus on data and services associated with public health (e.g. health and social care). We explored how data flows could be enabled through legal and IG frameworks, and how linked datasets across sectors could inform commissioning and research. To ensure the universality of the metadata specifications and accelerate its creation, we adopted existing specifications; e.g. data.gov.uk and Health Data Research (HDR) UK's Innovation Gateway [10]. Two metadata-specific workshops (one per LA) with data-related staff roles, facilitated by AH, were used to elicit perceived utility, barriers and solutions for developing metadata.

3.3 WP3: Workshops

A series of workshops and interviews were carried out between July 2021 and February 2022 (Table 1), conducted online (i.e. Google Meet or Microsoft Teams), led by SB and co-facilitated by MF. Interviews were carried out by SB. Appendix S2 describes: ethical considerations, research design, participant selection, data collection, data analysis. Verbatim quotations from participants are presented to illustrate key findings, selected to achieve balanced and overarching input from the organisations and groups.

3.4 WP4: Health economics

Workshop discussions (Section 3.3), bespoke meetings, targeted published and grey literature scoping reviews were conducted to explore two key areas:

1. Bridging the gap: evidence needs for local relative to national decision makers when quantifying and presenting the scope of outcomes and costs across sectors, and accounting for affordability relative to cost-effectiveness within relevant decision-making frameworks.
2. Health inequality: methodological research for incorporating health inequality considerations into EE (i.e. 'researcher-led' approaches), and how these compare to approaches within publicly funded commissioning agencies (i.e. 'commissioner-led' approaches).

Table 1: Overview of the workshops' and interviews' phases and groups

Phases (P#)	Group 1: Commissioners, directors, and clinicians	Group 2: Data analysts and researchers	Group 3: People with a legal or information governance role	Group 4: Members of the public
P#1: Initial discussion	Workshop #1	Workshop #2	Workshop #3	N/A
P#2: Further exploration	Interviews*	Workshop #4	Workshop #5	Workshop #6
P#3: Conclusions and recommendations	Workshop #7 and #8 cross-group workshops			Workshop #9

** The originally planned workshop was replaced by interviews due to poor attendance at Workshop #1*

4. RESULTS

4.1. WP1: Mapping review

Eighty case studies were identified from 71 documents: 31 were included for data extraction (Supplementary Excel S1). We contacted 15 individuals and organisations to provide missing data; however, often the data still could not be ascertained. Geographically, 12 of 31 included case studies were from London & South-East; others stemmed from West Yorkshire (Leeds/Bradford), North-West England (e.g. Greater Manchester), and the Midlands.

The case studies' information quantity varied considerably (e.g. one paragraph to 120-pages), with subjectively little correlation with 'quality' (i.e. our information of interest provided in detailed and meaningful manners). Studies were reported by diverse organisations (e.g. LAs, government programmes, charities) for different purposes (e.g. evaluation, promotion, sharing best practice), often for internal/local audiences rather than broader readership (e.g. researchers). Relatedly, project dissemination was varied; e.g. a few lines of website text, and/or a full project report, and/or even an accompanying YouTube video. We only found one case study (i.e. Kent Integrated Dataset) that had a peer-reviewed publication [11] and was one of a few appearing in several sources i.e. INVOLVE website and Nesta report [12, 13].

Case studies of most interest to our stakeholders generally involved cross-sector data sharing; e.g. Tower Hamlets Whole System Data Project monitors inequalities by linking LA data (e.g. rent arrears and library usage) to GP appointments and hospital admissions to inform resource allocation and commissioning decisions [14]. There were several instances of services using data to predict at-risk populations; e.g. falls prevention in older people (Nottinghamshire County Council) to Cheshire Fire and Rescue using nationally held GP practice patient registrations to identify over 65s for a "safe & well" visit [15, 16]. A post-hoc decision was taken to limit the number of COVID-specific studies, therefore only two COVID pandemic case studies moved to data extraction: Camden Council's "Analysing population-level data to identify areas of need", and Hackney Council's "Combining individual-level datasets to identify residents who are most clinically and economically vulnerable to COVID-19" [17].

There were few case studies where we were able to extract a full data set. Details of data-level shared (e.g. individual, household, or aggregate), sharing organisations and processors were often not reported; the perspective of commissioners was largely missing. Overall, the goal of sharing and linking data was rarely made explicit. Moreover, reporting the realisation of any public benefit was almost entirely absent.

4.2. WP2: Metadata

4.2.1. Developing a metadata specification and pilot catalogue: importance, challenges, and solutions

NHS mandated datasets are well documented by NHS Digital (a member of HDR UK's Health Data Research Alliance) using HDR UK's Innovation Gateway metadata specification. CCGs primarily make use of mandated, nationally standardised data returns from healthcare providers in England. A core responsibility of NHS Digital is ensuring the collection and appropriate dissemination of these data returns. In comparison to healthcare, there are few person-level mandated, standardised social care data returns. For our pilot, we focused on documenting data collected by our partner LAs' adult social care services; we were able to complete basic descriptive metadata (Table 2), but not comprehensive structural metadata.

During the metadata-specific workshops, participants universally acknowledged the usefulness of metadata throughout their organisation: frontline staff entering data, those responsible for the management and analysis of data, ICT managing software suppliers, and senior managers interpreting reports. Participants believed software/system suppliers should be required to provide metadata or, where applicable, appropriate tools to enable generation of their product-related metadata; however, this was generally absent. Participants felt recognition was lacking as to the importance of metadata from senior and executive-level managers which, combined with real-term funding cuts, lead to a lack of available skills and capacity to drive metadata development. Tables 3-4 provide suggested solutions to metadata development barriers.

Table 2: Descriptive metadata returns for Adult Social Care data collections

	City of York Council Adult Social Care data collections	Sheffield City Council people with adult social care services - snapshot
Abstract	The City of York Council's adult social care digital case management system and integrated financial case management system.	This table gives a snapshot of people currently receiving adult social care services procured or purchased by Sheffield City Council as at the end of the previous day, giving demographic information about the person and information about the services they are receiving.
Keywords	['City of York', 'Adult Social Care']	['Sheffield City Council’, 'Adult Social Care']
Description	The City of York Council uses [redacted] social-care case management software. Data are captured on people (current/ previous clients), and staff working in Adult Social Care. These are related through workflows, formed from one or more work steps (e.g. assessments, reviews, referrals). The council also uses [redacted] integrated financial case management system which links services attached to clients' care packages with their costs and providers.	People with adult social care services – snapshot. One line per service type the person is receiving.
Accrual Periodicity	CONTINUOUS	DAILY
Start Date	2002-04-01	
Time Lag	LESS 1 WEEK	LESS 1 WEEK
Jurisdiction	['GB']	['GB']
Data Controller	City of York Council	Sheffield City Council
Vocabulary Encoding Scheme	[’LOCAL','OTHER']	[’LOCAL','OTHER']
Conforms To	['LOCAL']	['LOCAL']
Language	['EN']	['EN']
Accrual Periodicity	CONTINUOUS	DAILY

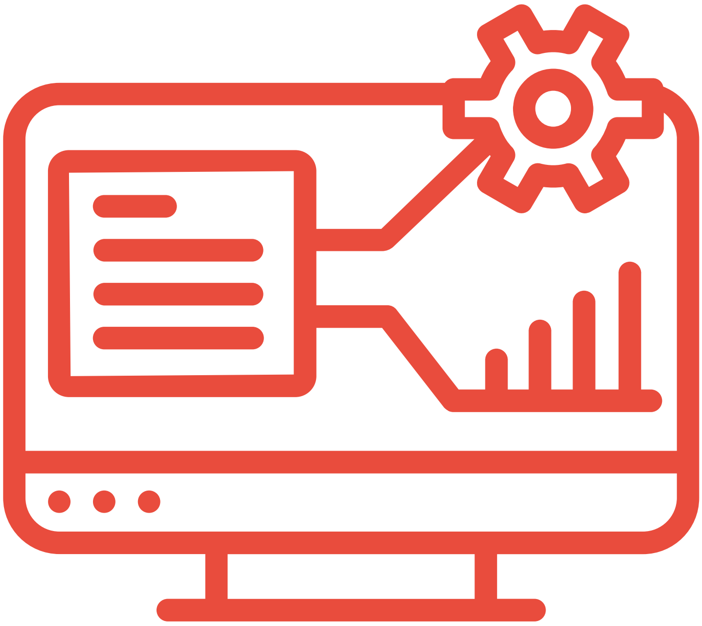
Footnote. *Some information has been redacted as it relates to third parties not involved in this project, therefore permissions to permit providing such information could not be sought i.e. [redacted].*

Table 3: Themes identified amongst proposed solutions for overcoming barriers in metadata development and associated quotes – organisational level themes

Theme	Quotes
ORGANISATIONAL LEVEL	
Recognition of importance of metadata at senior level	“How it [metadata] contributes to care by the most senior level of the organisation from executive to corporate management team that this strategic approach should be taken with data and why” “If you could put pounds and pence on how much is wasted because we don’t have metadata that would be a good step in the right direction. Recognition of the importance of metadata feels like it is about whole organisation acceptance not individuals.”
Better communication across departments	“Within the one LA we aren’t speaking to each other [regarding data] yet, let alone externally. Even within our organisation there is a need for people to talk [more] to each other.” “Amount of networking across LAs that was happening isn’t happening as frequently any more. Quality of the conversation isn’t as good as before, not seeing people face to face. A more dedicated solution-focused forum across LAs could be created. There isn’t a single forum. This would need to be supported properly with resources, communication (technical e.g., a library of information Wikipedia, not necessarily people time).”
Appropriate resourcing	“Funding should not be from internal budgets, it needs to come down from national budgets and be ring-fenced or it will hit cash starved budgets and moved elsewhere” “Organisations need to acknowledge that developing metadata is not going to be something we can do without resource. We need to agree a specification for minimum standard we expect for recording metadata.” “Then what to use it on (e.g. corporate data warehouse) and then how to resource that (development), then resource to maintain it, as over time the same field will mean different things.” “When there is pressure to deliver so much with ever diminishing resource it is difficult to say [developing metadata] is more important. It is about making an investment up front which will save you time and resource later down the line.”
Creating a staff culture	“Creating a culture amongst staff inputting data understanding how it does make an impact, the importance of it, caring about the quality and consistency of it, a culture where they care.” “Questions [around reported information] are often [about] metadata, metadata can bridge that gap, if it was sitting in the background as a library and users could find out what a field contains – managers are in fact asking for it, they are asking literally for metadata.”
Data quality standards	“Part of a local solution would be to have data quality standards. With a joined up architecture, with standards – making non-compliance visible so this can be addressed by the business.”

Table 4: Themes identified amongst proposed solutions for overcoming barriers in metadata development and associated quotes – suppliers of information systems/software and government

Theme	Quotes
SUPPLIERS OF INFORMATION SYSTEMS / SOFTWARE	
Product delivery	"Suppliers have to deliver a product that has utility application to build metadata. Market-wide standards come in here, [should be an] expectation that software is the smaller part of the product and [that] the robust documentation and what goes with it, weak on the metadata. Metadata seems to be an afterthought, a luxury, not intrinsic" "Ideally you would want to be creating an environment where metadata is part of the product when it is sold. Recognised as a necessary part of operating the system, having the metadata there"
GOVERNMENT	
Increased Government mandated data returns	"Statutory reporting to Westminster – where there is a national framework for reporting...you have to have centrally enforced data returns, that puts a tight constraint on the data"
Legal changes	"Before COVID we did some standard data sharing with the CCG, via NHS Digital (Data Services for Commissioners Regional Offices [DSCRO]). This was the only way to get health and social care matching up [linked], this is something that could be built on." "When you encourage sharing then the importance of metadata comes through. The Government needs to get something in law to share data as if we want to share, we know it will get blocked further down the road. The Government could do more to get us there and then it would be obvious that organisations need metadata."



4.2.2. Guidance on legal and IG frameworks to link data and enable data flows

Six key legal and IG frameworks and their role in regards to data access, linkage, and sharing were identified: Data Protection Act (DPA) 2018, UK General Data Protection Regulation (GDPR) 2018, common law duty of confidentiality, Health Service Control of Patient Information (COPI) Regulations 2002, section 251 of the NHS Act 2006, and the Health and Care Bill 2021 [4, 18-21].

A guide exists for understanding UK GDPR [19], the NHS Health Research Authority (HRA) provides GDPR operational guidance for research [22], and the Information Commissioner's Office (ICO) issues data protection guidance [23]. The UK GDPR 2018, tailored by DPA 2018, defines data protection principles, rights, obligations, including data:

- Controller: determines the purposes and means of processing personal data;
- Processor: responsible for processing personal data under the direction of a controller.

The common law duty of confidence, unlike DPA and GDPR, is not a defined document but based on legal precedent: broadly, information given in confidence, or under an expectation of confidence, must not be disclosed without the information provider's agreement unless for a valid lawful basis. In contrast to GDPR, duty of confidence applies to individuals' information even after death. Individuals' health and care information is generally considered 'confidential patient information'.

Where there are no practical means to obtain consent and a significant public benefit, the duty of confidentiality can be set aside under section 251 of the NHS Act 2006 [21]. This permits sharing confidential patient information for specific purposes without individual's explicit agreement, without the controller breaching duty of confidence. The HRA decides approval of applications under section 251, strongly guided by independent Confidentiality Advisory Group (CAG) advice who expect applicants to provide a mechanism for patient opt-out [24]; the data controller has the final data sharing approval decision. The Secretary of State for Health and Social Care can issue Notices under Regulation 3(4) of the Health Service COPI Regulations 2002 [25]; for managing the COVID-19 pandemic, these notices directed health and care providers (e.g. NHS Digital) to share confidential patient information with authorised organisations. Section 251 nor the COPI Notices remove the requirements for organisations to comply with UK Data Protection Legislation and NHS (or other appropriate) data security standards.

The Health and Care Bill 2021 is intended to dismantle many structures established by the Health and Social Care Act 2012, intended to reinforce the ambitions of the NHS Long Term Plan [1, 4]. It will allow NHS Digital to collect more information on medicines to analyse their use and safety, enable NHS England (amongst others) to publish data specifications detailing information which providers would be obliged to submit, and make it a criminal offence to share data inappropriately. The "Health and Adult Social Care: Information" section outlines requirements for providers to share 'anonymous' information - the bill doesn't enable sharing data beyond what is already permitted by GDPR, DPA, and duty of confidentiality.

4.2.3. Linked datasets across sectors to inform commissioning and research

Data provides huge opportunities to understand and provide solutions for improving health outcomes of patients and populations [26-28]. Addressing challenges to unlock data for direct care and secondary uses requires partnership between the data collectors, owners, guardians, and users. For example linked data across organisational boundaries could reflect the whole spectrum of care experienced by patients; e.g. linking hospice with secondary care data to identify where palliative patients might 'fall through the gaps' in care, then assess how to plug these gaps.

There are challenges to using and linking data across sectors and even specific care services, beyond the legal and IG considerations (Section 4.2.2). For example, information systems are designed to efficiently deliver a specific service with less consideration given to cross-system integration leading to data fragmentation within and between organisations [29]. Documentation (metadata) of source systems, their functions, data stores and flows is crucial to understanding what data exists and how it can be used. The UK's National Statistician states that: "Being able to link data will be vital for enhancing our understanding of society, driving policy change for greater public good and minimising respondent burden" [30]. The UK Government, Office for National Statistics, Administrative Data Research (ADR) UK, and HDR UK all have corporate strategies that include increasing linked data usage [31-34]. This requires data sharing across organisational boundaries; however, identifying, agreeing and documenting data sharing initiatives is not routine practice. In case of doubt, organisations are likely to avoid data sharing risks, but also subsequent potential benefits [35]; trust is important for the use, linkage, and sharing of data [36].

The COVID-19 outbreak increased needs for regional, national and international population health management, stimulating significant developments in routine and linked data use; e.g. NHS COVID-19 Data Store [37]. The NHS's single data strategy, Life Sciences Vision, and UK Clinical Research Implementation Plan, envisages more widespread health and care system data use in driving insight to support population health, resource planning, clinical research and health-improving innovations [26, 38, 39]. To enable this, the secure, privacy-preserving "Five Safes" framework is beginning to be adopted in health and care research [40]. Within this framework, research data are linked and de-personalised by independent accredited data processors to reasonably ensure inability to re-identify persons or businesses; researchers and their projects must be accredited before gaining access; data can only be accessed within an accredited safe environment; and all research outputs are independently checked to ensure they meet statistical disclosure control guidelines. Transparency and conformance to consistent access and governance standards is important to aid public and care professionals understanding and confidence around data protection.

4.3. WP3: Workshops

Nine workshops and five interviews were conducted across 18 staff participants: LAs, five each; CCG, six; two from two Universities. Table 5 includes a summary of associated attendees; some participants attended multiple workshops and/or an interview. Seventeen people attended the two public workshops.

Four main recurring themes were identified: context and timing; the need for a different approach; obstacles and enablers (i.e. governmental and legal; organisational; process factors); challenges in communicating information to the public. Verbatim quotations support theme-specific narrative summaries (Tables 6-11).

Table 5. Summary of participants

Workshop #	Summary of attendees*
Workshop 1	Three attendees, all senior staff within a CCG
Workshop 2	Five attendees, people with data analysis role from 1 CCG, 2 LAs and 1 university
Workshop 3	Four attendees, people with legal or information governance roles from 1 CCG and 2 LAs
Workshop 4	Seven attendees, people with data analysis roles from 1 CCG, 2 LAs, and 1 university
Workshop 5	Five attendees, people with legal or information governance roles from 1 CCG, 2 LAs, 1 university
Workshop 6	11 members of the public and three public advisors
Workshop 7	Seven attendees, individuals who had attended a prior workshop or interview
Workshop 8	Eight attendees, individuals who had attended a prior workshop or interview
Workshop 9	13 members of the public, together with 4 members of the study public advisory group.
Staff interviews	Two clinical service leads, one commissioner of services, two senior data analysts.

** Eighteen staff: five from each LA, six from a CCG, two from two Universities. Seventeen public members.*

Theme 1: Context and timing

Relevant context included current relative to new system configurations; e.g. ICSs. Views varied as to whether these reconfigurations provided a positive context for change, or bad timing for new data arrangements (Table 6, #1-3). The COVID-19 pandemic was a challenging context, skewing organisational priorities while indicating what data aspects could be achieved e.g. data sharing enabled by the COPI notices (Table 6, #4-5). There were positive views that progress enabled by the COPI notices might be sustained; however, other participants were concerned that gains might be lost (Table 6, #6-7). Finding legitimate, legal ways to continue progress was considered an important priority (Table 6, #8). The Health and Care Bill 2021 was perceived as an opportunity for change; however, many participants were pessimistic if it would permit new cross-sector data sharing arrangements (Table 6, #9-10).

Theme 2: A different approach

Data interpretation and understanding is key: data needs useable forms for non-analysts (Table 7, #1). A gap exists within, but particularly between, organisations of understanding available data useful to answer key commissioning and public health questions (Table 7, #2), with the need for “a different approach” apparent. Organisations have different priorities and drivers; progressing forward requires seeing “the bigger picture” that sharing data is a joint-interest which requires enhanced communication and co-operation (i.e. between commissioners, researchers, and the public). Some LA participants described a “medical model view”, with health services not appreciating LA data’s value for population health decision-making (Table 7, #3-4)

The ability to have and use certain data is related to organisation’s functions, thus requiring strategic thinking about data sharing (Table 7, #5). LAs’ broad remit of services/functions (e.g. social care) requires approaches and confidence that LAs will use shared health data appropriately, aligned with their functions; this is also true for sharing non-NHS data with NHS services/commissioners.

Theme 3: Obstacles and enablers

Subtheme 3.1: Governmental and legal

National-level structures (e.g. government departments) lead to information being processed in different ways, with different advice issued to NHS versus LAs, and within/between LAs (Table 8, #1). There is frustration associated with sharing data (Table 8, #2-4). The purpose for collecting (then sharing) data is not always clear, highlighting that data protection balances are important (Table 8, #5-7). In contrast, pandemic-driven COPI notices had clear purposes for data sharing (Table 8, #8).

The NHS Act distinguishes the role and function of the NHS relative to LAs on different legal bases. LAs may only access data for commissioning/population health purposes, separate from their other service provider role (Table 8, #9). Organisations’ legal requirements relating to purpose versus function is important, but also a potential source of legal solutions for data use/sharing (Table 8, #10).

Subtheme 3.2: Organisational

Organisational senior-level buy-in is needed to set the right culture and risk-appetite regarding IG and data sharing (Table 9, #1-2). Limited capacity/capability/skills to clean and interrogate data, and limitations of current data systems were perceived challenges (Table 9, #3-4). Differing organisational priorities and perspectives affected data sharing; how data could inform budget-constrained decision-making differed between NHS versus LA commissioning cycles and financial years, with LAs also affected by being ‘fragmented’ organisations (Table 9, #5-6).

Subtheme 3.3: Process

Interlinked data is lacking: obstacles to data sharing and uses often relate to data processing (Table 10, #1-2). Data recording inconsistencies or omissions between organisations/services makes comparability and usefulness restricted (Table 10, #3). Individual organisations often have their own local data system configurations; modifiable/customisable software makes ‘consistent’ data and then sharing an issue, alongside software provider intellectual property issues (e.g. transparency) (Table 10, #4-5).

Linking data is challenging using fully anonymised data (Table 10, #6-7). Complications and confusion arises around operationalising data defined as ‘anonymised’, ‘pseudo-anonymised’, ‘personal’, and ‘de-personalised’ – pseudo-anonymisation particularly requires further clarity (Table 10, #8). Processes to enable data sharing exist, but can be lengthy and frustrating, with lack of clarity around pre-existing and potential legal and IG gateways alongside organisational functions (Table 10, #9-10).

Theme 4: Challenges in communicating information to the public

Addressing public concerns requires clear communication around responsible use and sharing of patient/client data for public benefit (Table 11, #1-2). The public appear aware of contextual factors such as changes in healthcare structures (e.g. ICSs), but voiced uncertainty whether this "would change everything". Considerations about how data might be used for public benefit are pertinent; e.g. for particular population subgroups (Table 11, #3-5). There's uncertainty regarding data quality (e.g. accuracy and completeness) with diverging views regarding data protection (Table 11, #6-9).

During WP1 case study discussions, it became apparent there's lack of public clarity when 'data' might be related to individual health records being shared to improve direct care, relative to non-individual-level data (e.g. aggregated), secondary uses (e.g. commissioning), and associated public benefit (Table 11, #10-13).

Recommendations for action

Participants suggested change could and should take place at different levels, both internal and external to organisations, as summarised in Table 12.

Table 6: Theme 1 verbatim quotations – context and timing

No.	Quote	Workshop/Interview
#1	The ICS guidance says that data sharing will be for local determination, but the current legislation doesn't allow it.	Interview 3
#2	The White paper hints around improving facilitation of data linkage, but it's a long way off	Data analyst workshop
#3	All the impending changes in ICS, ICBs etc...there has to be a change in the law on data sharing for these new structures to work....there absolutely has to be as these new structures can't legally work under the present system	Combined workshop
#4	We will see if this opens things up. COPI shows that LAs and NHS can meaningfully share data to improve health	Legal and IG workshop
#5	Increased information sharing, in Covid was a response to the extraordinary circumstances we were in. The reality is that it is being worked through and the emergency is ending. Organisations will rightly revert to mainstream approaches on the frameworks that exist	Legal and IG workshop
#6	More opportunities are presenting themselves so might not revert or land somewhere better...we have more people in organisations who understand the data sharing landscape, will be a lot of push from NHS and LA so things don't revert back	Data analysts workshop
#7	When we step down from the command and control structures people seem to go ....that's over lets go back to the thing we did before which we know didn't work	Interview 3
#8	We need to find a legitimate legal way of doing what we have been doing over the last 18 months realistically on a day to day basis going forward	Legal and IG workshop
#9	A step forward would be if contains powers for bodies to share information to better enable their functions	Legal and IG workshop
#10	The new Act going through parliament,,,.referred to changing the law to improve data flow for commissioners so I suspect that will be just for commissioners/NHS	Interview 4

Table 7: Theme 2 verbatim quotations – a different approach

No.	Quote	Workshop/Interview
#1	The way the data relates to actual practice is the tricky bit and the bit you need to understand if you want to interpret it correctly	Data analysts workshop
#2	We have not sat down each year and said what data do we need for our new business model, we have a model which works, it flows some data over, we just say let's keep doing that until we have a model which comes up with a better idea. I can't remember the last time I sat down with anyone from the council and said have you got anything new and exciting which you could give us	Data analysts workshop
#3	The CCG don't seem to come to us ever for our data, they don't seem to need it. We could share it if we got the agreements in place, but they don't seem to have a need for adult social care data	Data analysts workshop
#4	Part of it is a lack of understanding from the CCG on how they could use LA data, we know how we could use GP data. I have been trying to stimulate that conversation for years	Data analysts workshop
#5	Any changes in legislation would have to focus on the purpose of data sharing and give new powers for bodies to share information to better enable their functions	Legal and IG workshop

Table 8: Subtheme 3.1 verbatim quotations – governmental and legal obstacles and enablers

No.	Quote	Workshop/Interview
#1	Things are disjointed...two white papers, one on levelling up, one on disparities being run by separate departments and separate civil servants – if we could have some sharing here would avoid some of the mess	Data analysts workshop
#2	LA don't share with health, not that they won't share they can't – in NHS IG means we can't look at any identifiable data from any external source. If a small data set a LA would have to put a block on it, not even just aggregate, area could be known and be able to pick people out. LA would love to push the button on it, it would make all our lives so much easier, but if any of us receive it we would have to report and you get fined for sharing information out of the IG clearance	Interview 2
#3	I can see data for people but can't see for housing as it doesn't sit with people	Data analysts workshop
#4	The CCG does not own NHS data so cannot give it to LAs	Legal and IG workshop
#5	What we tend to do is collect lots and lots of information.... without always knowing what we are collecting it for. I am not sure we have got the point of having a purpose and then this is what we need to collect ...it tends to be collect it and then we'll work out what we need it for	Interview 1
#6	Important to decide what benefits sharing would have and only share what would have benefits not just share everything because it's a good idea	Interview 2
#7	Legislative frameworks always have to strike the balance for individuals, to ensure safeguards for individuals	Legal and IG workshop
#8	The critical issue was we were able to make a very strong consistent case for why we needed access to the data – health protection	Legal and IG workshop
#9	We hit buffers regarding what the council are responsible for versus what the NHS are responsible for. Those purposes don't align. Data we held for one purpose couldn't be sent to the council for another purpose. The council can share data with the CCG at a person level legitimately but I can't send that data back to the council	Legal and IG workshop
#10	You could manage that in legislation with a clear legislative boundary – move from function to purpose – so if there was a legal gateway saying that health information could be shared between health organisations and social care organisations for the purpose of improving health and social care outcomes – make that subject to sets of boundaries in regulations and guidance you have the enabling provision and you can put safeguards around that. So moving it out of function and into purpose. This is me imagining brand new legislation which would be like a magic wand	Legal and IG workshop

Table 9: Subtheme 3.2 verbatim quotations – organisational obstacles and enablers

No.	Quote	Workshop/Interview
#1	Sometimes we are more anxious about information sharing risk than we need to be	Legal and IG workshop
#2	The buy in from senior management helps, in the initial phase is crucial because of the amount of work from staff required. Can somebody spend 3 months…requires massive investment of time and money, understanding of the potential benefits	Data analysts workshop
#3	People are not trained to question the data, trained to produce data over the years….that is the part people are struggling with…what is it telling me what do I want to do now	Interview 3
#4	A factor is also interoperability of IT systems and infrastructure, not just staff capabilities, but also IT capabilities if you are pulling data from different systems your ability to bring it into a warehouse or whatever, the ability to handle large volumes of data, and the controls you can bring in to that process	Legal and IG workshop
#5	We [the LA] are more outcome focussed…we sometimes find the NHS….quite constraining…the way they do their contracting is very prescriptive….we work on a yearly basis…. we try not to but when your budget is stretched it is what you do	Interview 1
#6	[LAs are] sensitive to the boundaries they are operating in, sensitive about enabling legal powers, and cautious over pushing against boundaries.	Legal and IG workshop

Table 10: Subtheme 3.3 verbatim quotations – organisational obstacles and enablers

No.	Quote	Workshop/Interview
#1	The data linkage and anonymisation process is not simple, and the complexity has time and resource constraints	Data analysts and researcher workshop
#2	If you want to do anything with the data that is not related to hands on patient care the data is around 2 months behind	Data analysts workshop
#3	Liquid Logic is local authority data but there isn't a data dictionary or national data set. It is not a criticism....it is a different world....not coded in the same way....the quality is different	Interview 4
#4	It might be the same database as the same company build it, but the interpretation of data might be different because of the way we set things up in system terms	Data analysts workshop
#5	There are restrictions how you can distribute the information, LAs are a client of the company so they have to be careful what they distribute	Data analysts workshop
#6	For me once I can pick out a person I can see the story of what has happened to that person. Problem is still building that initial timeline of people. Starts in LA, then adding GP, in hospital, what have voluntary sector contributed	Interview 5
#7	We don't need names but we need personal characteristics, we have to be able to distinguish – you have got to know age, ethnicity, gender or you can't do this properly	Legal and IG workshop
#8	Unless we use pseudonymised data in the correct way we are going to carry on with siloed working. The technology is there why can't we use it – surely it can't be that difficult to get a clear definition of anonymised and pseudo-anonymised data	Legal and IG workshop
#9	We each have a gateway for a specific purpose, what you need it for today – if you want to stray off that course, not quite in the scope for what you have access for you have to go all the way back through the process – that is the frustrating bit	Legal and IG workshop
#10	There are solutions but they are long-winded and you have to specify specific purposes to sharing the data. Because of the many functionalities in the council that could be a problem	Legal and IG workshop

Table 11: Subtheme 4 verbatim quotations – challenges in communicating information to the public

No.	Quote	Workshop/Interview
#1	Have had objections from patients [named area] has highest proportion opting out but these people are in the highest area of need	Data analysts workshop
#2	There is an appetite from patients for this. They want organisations to talk to one another but don't want them to sell data commercially	Data analysts workshop
#3	Areas with poorer health can be a different story to other more affluent areas	Public workshop
#4	How is this data going to help who are ethnic minorities or is it we don't understand their lifestyle so we are not going to do anything...how is this data going to help ethnic minorities	Public workshop
#5	You can collect as much data as you want but will it help.... some people just don't want to change	Public workshop
#6	Data is only as good as people coming forward with information about their health"; "where is data coming from, is it people going to their GPs or people going to hospital	Public workshop
#7	One thing concerns me is the accuracy of the data that is being used to make major decisions"; "accuracy of data and who you rely on for your sources so for example data from medical tests would in my opinion not be reliable	Public workshop
#8	More and more people are saying no to sharing data because you hear about data breaches all the time	Public workshop
#9	There is protection, if the numbers in a particular group get too small it is dropped. My experience of using data is that it is very strong. Groups undergo very heavy checking from NHS departments to keep the data safe	Public workshop
#10	It would be nice to know what particular conditions we are talking about, the case studies didn't indicate that	Public workshop
#11	The benefits to patients should be highlighted better, should be an opportunity for patients to say this is what we want to get out of this	Public workshop
#12	The data would be helpful if the benefits are highlighted better, the benefits of what they are doing need to be pinpointed	Public workshop
#13	The aims might be good but the public need to know how they got to deciding these aims	Public workshop

Table 12: Summary of actions from the workshop discussions

No.	Actions at a national level
1	Clearer legislation to enable data sharing
2	The provision of legal gateways for data sharing
3	Examination and clarification of the status of pseudo-anonymisation and associated legal perspective
4	Issues of limited resource for data analysis need addressing, particularly for LAs.
5	Government departments should provide consistent messages and actions across and within sectors

No.	Actions for organisational leaders
1	There should be senior-level, system leadership on data sharing
2	There should be nominated responsibility for data sharing within organisations, with a dedicated senior role and transparency regarding who the “go to” people on this aspect are
3	Organisations should be proactive in examining data systems and building on local efforts and prepare for change happening
4	At a senior leadership level improved data sharing should be viewed as an opportunity not a risk
5	There is a need for local processes to be set up which provides a forum for discussion and action on improved data sharing with a focus on determining local solutions
6	There should be appreciation of the requirement for new ways of working, with appreciation of the benefits of a collective approach for the whole health and care system and benefits for the local population
7	There needs to be examination of the capacity for data analytics in and across organisations and how and where priorities for budgets should be established.

No.	Actions for those in data roles
1	There should be work towards development of optimal data integrated architecture, data views, a system of systems approach
2	There should be action to develop greater consistency in data across organisations
3	The development of mechanisms/forums to enable greater sharing of knowledge regarding who has what information available, knowing how and when to use it, and who can use it best should be a priority.
4	There should be exploration of development of minimum standards at organisational level
5	Data owners should be clear in knowing what are able to share and seek full understanding of the legal/IG basis
6	Locally agree objectives, making sure organisations come together, and work on shared priorities
7	Given the changing organisational context a priority should be understanding how data sets flow in a new environment (ICS, changing geographies, etc.).

No.	Actions for those in public engagement roles
1	Need for greater public buy in to the concept of data sharing for strategic decision-making
2	This will only be achieved by work to increase levels of understanding amongst the general public
3	Organisations should focus on communicating clarity of purpose for sharing data and the benefits for the local population.

4.4. WP4: Health economics

4.4.1 Bridging the gap

Context. Researcher-driven EE frameworks such as cost-effectiveness analysis (CEA) have primarily been employed to maximise quality-adjusted life years (QALYs) subject to a care system's budget constraints. While there are additional considerations that have been incorporated into these frameworks (e.g. inequality impacts; Section 4.4.2), the primary concern is headline cost-effectiveness: if additional health gains (e.g. QALY gains) from a proposed course of action are worth additional costs relative to the next best alternative(s). At a national-level (e.g. NICE), EE applications are distanced from explicit political, practical, and budgetary pressures often evident in local decision-making. EE evidence is less integral to local decision-making processes, due to perceptions (or reality) that it is undesirable and/or inappropriate [41]. Here we summarise four areas of contention that emerged through our discussions with the LAs and CCG: budgets, costs, timing of expenditure alongside affordability, and data integration and access.

Budgets. While NICE-related EE generally considers a central budget that is fixed in scale but can be reallocated between programmes, each CCG and LA are allocated central government funding, with LAs also able to raise funds from local taxation, service fees, and other sources (e.g. investment returns) [42]. Budgets – the relevant monetary amount available to spend – that cannot/can be exceeded are hard/soft. In reality, such distinctions are not clear nor binary; e.g. LAs face statutorily ring-fenced funding (e.g. central government grants) alongside funding statutory services (e.g. waste collection) [42, 43]. Relatedly, organisation-level budgets are high-level budgets assumed to be hard, e.g. due to statutory obligations placed on LAs to prevent budgetary overspend [42, 44]; whereas programme budgets are allocated to organisations' particular services or programmes. Local decision-makers may be able to reallocate funds between programmes; although costs resulting from the same decision may fall on multiple programme budgets (e.g. public and medical health) or multiple organisations (e.g. central vs local government, CCGs vs councils). Concerns regarding intertemporal spending can arise from legal and accounting requirements e.g. medium term financial strategy [42, 44]; further non-statutorily-induced time preferences may arise out of political budget cycles [30]. Therefore, the consideration of a single budget that can be allocated over the longer-term does not reflect local decision-maker realities.

Costs. Conventional EE applications assume commissioners' current or new service costs are flexible and portable; in reality, there are different costs for consideration [7, 45]. Fixed costs are volume independent (e.g. rent) whereas variable costs are volume dependent (e.g. staff); sunk costs are irrecoverable once incurred (e.g. building a hospital ward) with friction costs associated with transaction execution (e.g. closing a hospital ward). These could be associated with implementation (e.g. initial training), intervention (e.g. new ward), or future costs (e.g. downstream care) [7]. As such, local decision-makers need to consider multiple cost types landing across multiple organisation-level and programme-level budgets at different time-points.

Expenditure and affordability. While cost-effectiveness is often judged on a mean cost-per-unit ratio across individuals (e.g. cost per QALY), affordability is a related but less considered concept [46, 47]; e.g. a new programme costing £4m given a discretionary £1m budget is unaffordable even if cost-effective. While programme affordability considerations are less common in national decision-making contexts where budgets are large, they are more prevalent within local decision-making with smaller and harder budgets [48]. When considering expenditure relative to affordability, a common assumption is that timing is largely unimportant with high impacts smoothed over time; however, local decision-makers cannot always borrow money to fund cost-effective options with substantial up-front costs (e.g. implementation), even if future rates-of-return exceed borrowing interest rates. Also, uncertainty regarding expenditure (e.g. a programme remaining within budget) is likely to pose greater problems at local relative to national-levels.

Data integration and access. All these quantifiable aspects – costs, budgets, and expenditure – require relevant, accessible, and accurate data. While the NICE reference case imposes clear and strict information requirements on those submitting new technologies for health technology assessment (HTA), no such statutory local-level structures exist [49]. Additionally, local decision-makers seldom have time or finances for primary data collection; although some routine data does exist, it is often not as extensive, accessible, reliable, or timely as local commissioners need to inform robust decision-making [29]. In terms of budgets, this information may be known only to specific job roles (e.g. finance managers) and not wholly known with certainty at any given time. NHS Digital has mandated (minimum) datasets [50], reported across the vast majority of NHS services which reflects activity data (e.g. hospital spells via Hospital Episode Statistics data) and cost-codes (e.g. Healthcare Resource Grouper for calculation of Trust payments) [51]. Local NHS decision-makers can use local service data flows within their geographical jurisdiction among other datasets e.g. Secondary Uses Service (SUS) [52]. Non-NHS sectors and within specific NHS services (e.g. GP data), data access and knowledge is more complicated; e.g. social care has no mandated metadata, meaning limited knowledge and understanding of such data which could lead to issues when supporting cross-sector commissioning as supported by the Health and Care Bill 2021.

Bridging the gap. Although alternatives to CEA are available, including alternative HTA-associated approaches, multi-criteria decision analysis, and programme budgeting and marginal analysis (Appendix S3 provides an overview of these approaches); no one framework accounts for all the realities faced by local decision-makers, but each include aspects of pertinent consideration. As such, ways to bridge the gap could be sourced from existing methods and frameworks, but require detailed knowledge and data to facilitate.

4.4.2. Health inequality

Context and researcher-led approaches. The understanding of commissioning decisions' impact on health inequality plays a role in both researcher and commissioner-led considerations. Analytical methods to account for inequality concerns alongside CEA include equity 'impact' or 'weighting' approaches [53]. Avancena and Prosser's systematic review of CEAs incorporating equality considerations identified 54 studies, with the majority using an equity impact approach (n=46) [53]. Equity impact analysis produces summaries of cost-effectiveness stratified by sub-groups of interest, then reports the respective costs and health outcomes for each stratified group alongside headline cost-effectiveness summaries for the full population. In contrast equity weighting methods, often called distributional CEA (DCEA), additionally incorporate differential QALY weighting, allowing for total population health and inequality trade-offs [54].

LAs. Despite LAs' public health remit, there is little legal requirement or good practice guidance to facilitate their health inequality alleviation attempts [1, 55, 56]. LAs' variable actioned responsibility to reduce localised group inequalities was demonstrated in Just Fair's 2018 report [57]. Just Fair identified data-aspects as two of five tackling inequality features: 'meaningful data assessment' and 'using data effectively' [57].

CCGs. CCGs' remit includes reduction of inequalities in access to, and outcomes from, healthcare, and reflected in their funding allocations from NHS England [1]. Inequality is considered in the Oversight and Assessment process, under which NHS England conducts statutory annual CCG assessments, recording data on aspects of 'preventing ill health and reducing inequalities' (e.g. fall injuries in people 65+ years old) [58].

ICSs. ICSs intended modus operandi is 'improving outcomes and addressing inequalities'; however, how this will be operationalised and monitored by NHS England are limited to high-level aims outlined in the White Paper [59]. However, from the White Paper and CCG experience we can infer a likely potential two-level approach to inequality: one focussing on inter-ICS comparisons to inform funding allocations, the other focussing on within-ICS geographical inequality needs and challenges. This risks potentially inconsistent pressures within ICSs as they attempt to grapple with their jurisdiction specific health and inequality considerations alongside broader inequality measures for inter-ICS comparisons [60].

Aligning the approaches. To discuss how the researcher-led and commissioner-led approaches can come together and associated potential benefits, it is important to consider their relative practical and methodological strengths and limitations (Table 13), alongside available data to quantify key inequality characteristics (Table 14). Indicative of the challenges of identifying data in these contexts, there are examples where we were unable to conclusively determine a potential data source; these are labelled 'unknown' in Table 14, which occurred mainly within a LA context.

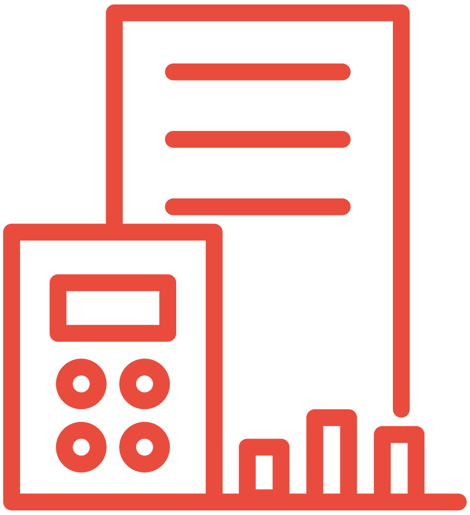


Table 13: Potential benefits and limitations of researcher and commissioner-led approaches to quantitatively account for inequality considerations related to their applicability to local commissioners

Approach	Potential strengths	Potential limitations
Researcher-led approach (i.e. DCEA)	a) Compatible with existing methods of economic evaluation conducted by groups such as NICE as well as informative to some health-related commissioning decisions. b) As a broad method it is flexible to the definitions of equality subgroup and the measure of health maximising c) Explicitly demonstrates the trade-off between total population health and inequality DCEA; thus allowing formal debate over the appropriate level of inequality aversion.	a) Requires a full CEA to be conducted; thus can be complex and costly to implement, and risks the ability for locally tailored analyses. b) In DCEA's current form it requires a single definition of inequality around the health outcome that is being measured, e.g. QALYs; thus limited flexibility to fully inform cross-sectoral or broad stakeholder deliberations. c) There are outstanding questions regarding both the appropriate means of estimating society's aversion to inequality and the level of aversion it implies; additionally there are issues when framing the inequality question which can impact on the public's level of aversion [67]. d) Risks oversimplification by overlooking structural elements that cause health inequality and inequity.
Commissioner-led approach	a) By summarising multiple measures side-by-side, the approach does not necessitate an a priori value set of inequality aversion, allowing different stakeholders, with potentially different views on the population health inequality trade-off, to use it. It is therefore more readily useable to inform multi-stakeholder discussions including formal methods such as multi-criteria decision analysis. b) The simplicity of reporting and positioning of the analyses makes access to real-world and timely data much easier and therefore responsive. c) Due to its development to directly inform commissioning and funding decisions, the simple reporting of health-related inequality measures is responsive to the needs of local decision makers and the budget setters in central government	a) Simple summary measures of inequality and ranking of performance by area implicitly makes complete equality as the perfect solution where, as a corollary, inequality in the measure is zero; thus risks placing focus on inequality rather than health burden, while ignoring the existence of inequalities that may be unavoidable. b) The focus on ranking or performance by area risks perverse incentives around performance, with stakeholders aiming to do just well enough in each measure rather than focussing on individual health. Additionally, the use of ranking risks dis-incentivising collaboration. c) Lack of a unifying, a priori, definition or quantification of inequality results in case-specific analyses; thus of limited use for cross-comparability within unified budgets. d) The quantification of inequality by which performance is assessed, are often defined in terms of care utilisation or individual behaviour (e.g. smoking) rather than overall health (e.g. life expectancy), which are proxies of health. e) Due to the nature of the available data much of the narrative around inequalities in this context relates to geographic groups (i.e. LSOA groups) rather than unique to patients; e.g. IMD quintiles are allocated to patients based on the IMD score of the LSOA of residence, risking groupings that do not reflect the individual. f) The lack of a minimum or maximum set of inequality measures, with the variable set often determined by data availability, risks measures of limited relevance being included in deliberations, or relevant ones excluded.

Table 14: Potential NHS and LA data sources to quantify health inequality and associated targeted characteristics at the person or regional level

Characteristic or health inequality	NHS data source	LA data source
HEALTH INEQUALITY EXAMPLES		
Care resources consumed	Various NHS datasets covering NHS resources	Social care and care homes (LA-funded only)
Health profile measure (e.g. generic or condition-specific PROMs)	Hip and knee replacement (e.g. EQ-5D-3L); IAPT (condition-specific e.g. GAD-7 and PHQ-9)	Unknown [c]
Determinants of health (e.g. smoking)	Primary care	Possibly LA property tenancy data and LA-funded social care data
OTHER USED/RECOMMENDED CHARACTERISTIC EXAMPLES		
Age	Common across NHS data sources	LA-funded social care; many other council services
Disability	Potentially primary care, admitted patient care, others	Disabilities facilities grants; LA-funded social care
Gender reassignment	Not routinely available (results in new NHS number creation). Present in some MH and primary care data.	Unknown [c]
Marriage and civil partnership	Present in some MH-related data, Maternity services dataset, and most health records	Unknown [c]
Pregnancy and maternity	Maternity Services dataset and primary care records	Unknown [c]
Race (and ethnicity)[a]	Ethnicity is common across NHS data sources (known issues with completeness of data)	Some council services (e.g. social housing)
Religion or belief	Not routinely available.	Some council services (e.g. social housing)
Sex	Common across NHS data sources	LA-funded social care; many other council services
Sexual orientation	GUMCAD Sexually Transmitted Infection Surveillance System Data Set (not linkable)	Unknown [c]
2010 EQUALITIES ACT - NINE PROTECTED CHARACTERISTICS		
Socioeconomic status	Not routinely available	Stop Smoking Services Quarterly Data Set
Index of Multiple Deprivation (IMD)[b]	Derived from postcode, captured for most NHS contacts	Derived from postcode, routinely used within LAs

Acronyms. LA, local authority; MH, mental health; NHS, National Health Service; PROMs, patient-reported outcome measures.

Footnote. This table should be considered representative of possible data source examples, and should not be considered a fully comprehensive list of possible data sources for where a characteristic or health inequality is quantifiably stored or not.

[a] The 2010 Equalities Act specifically refers to 'race'; however, for the purpose of this table we refer and reflect on race and ethnicity.

[b] IMD is not a 'patient-level' metric as it is geographically defined based on the characteristics of the resident population of small areas i.e. Lower Layer Super Output Area (LSOA).

[c] Unknown implies that through discussions with university, LA, and CCG representatives as part of the Unlocking Data project, an appropriate data source could not be suggested.

5. HOW TO UNLOCK DATA FOR POLICY AND PRACTICE

Conducting a grey-literature mapping review was time-consuming and cumbersome, with key data missing. Although grey literature need not adhere to reporting standards, it was surprising the Data Controller and Data Processor were often not transparently reported. In order to increase public understanding and buy-in, organisations should openly publish how such sharing and linkage has been used and the realised public benefit; this need was also evident from our workshop discussions.

There are legal gateways and IG frameworks to permit responsible use of data; although, there is confusion and frustrations with these current pathways.
Use and sharing of data has increased due to the COVID-19 pandemic, enabled by the COPI notices; there is hope such progress will continue to be enabled once these notices (in their current format) cease. However, without appropriate metadata, data discoverability and understanding will be a hurdle for use of non-NHS data and so should be priority. In the longer term, collaborations across sectors and with universities should broaden, relevant skills sets across disciplines and sectors should be funded to grow and merge, with increased use of responsibly linked data promoted allowing analysis across research and commissioning questions for public benefit.

Researcher-led evaluation frameworks to enable use of data do not always meet the needs and realities of local decision-makers; additionally, the data is not always known, available, or usable for such frameworks. There are various barriers to overcome to enable consistency across researcher-led and commissioner-led approaches; e.g. finding a common set of vocabulary around definitions (e.g. health inequality), and agreement on how aspects are quantified and then presented to inform decision-making both at local and national-levels. There are barriers likely to be perpetual in the alignment of approaches, such as commissioners' requirement to place their legal duty at the heart of any commissioning decision, and the cost and skills for data analysis and using associated evidence. However, current research-led quantitative frameworks could be used to inform commissioning if there was more alignment in understanding, alongside funded job roles and skills; how such evidence would be aligned with payment structures is an area for further research. Our recommendations are presented alongside our Summaries.

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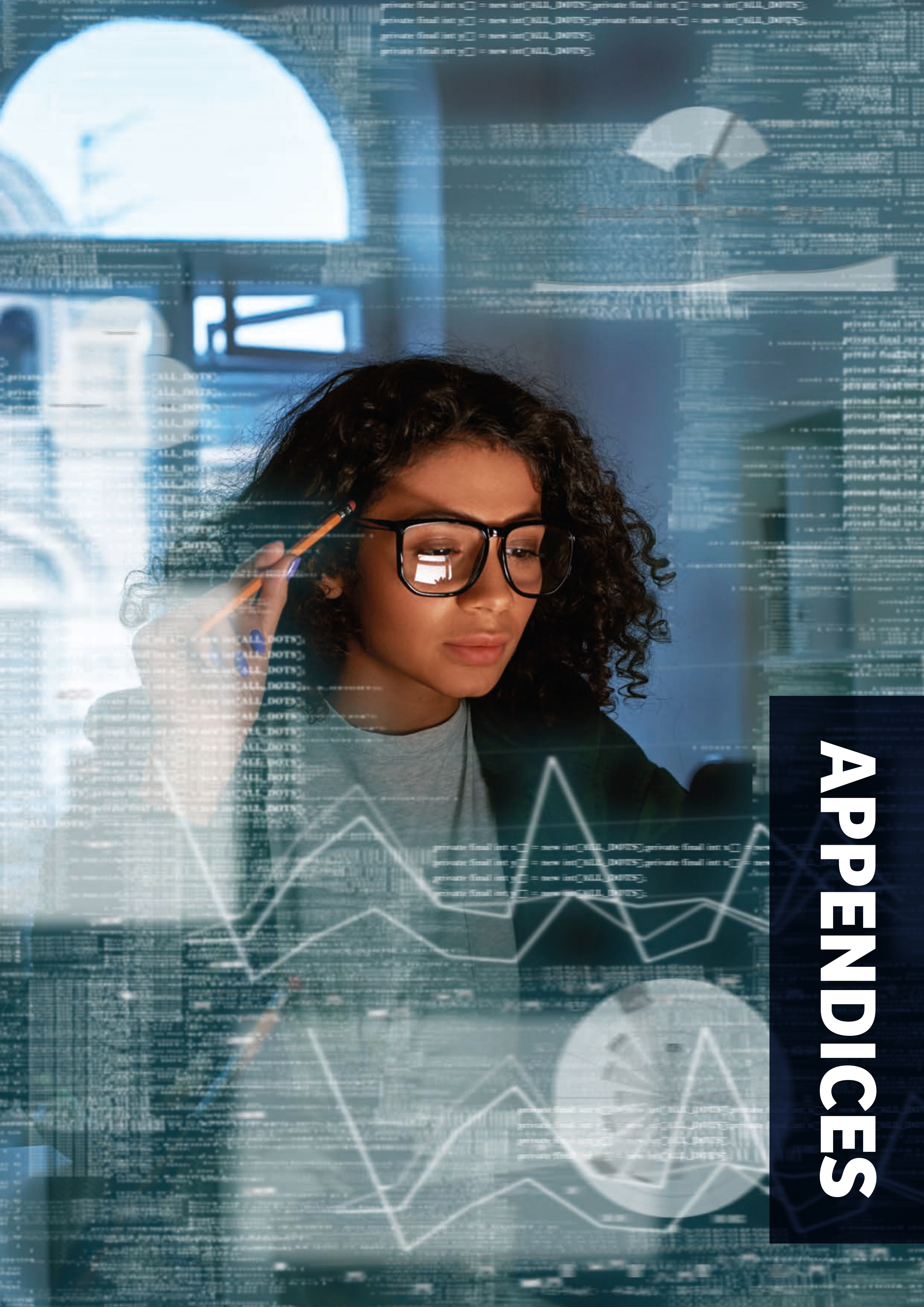
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APPENDICES

APPENDIX S1: WP1 MAPPING REVIEW SUPPLEMENTARY METHODS AND TABLES

Phase 1: Grey literature source identification and search

Through consultation with our SSC and SMG, case study inclusion and exclusion criteria (Table S1.1) were pre-agreed before constructing a source database provided in Supplementary Table S1.2 and Table S1.3. Websites were searched using a combination of: Google's advanced search interface; websites' search interface; bespoke browsing (i.e. not search term nor interface driven). Due to a lack of advanced features for systematic searching, the aforementioned searches were iterative; Table S1.4 provides an indicative list of search terms used in various combinations based on the three overall concepts of interest: (1) data processes; (2) types of data; (3) geographical. An ideal search included concepts 1 AND 2 AND 3, but where that retrieved nothing, we tried (1 OR 2) AND 3, with 3 often being implicit based on the geographical focus of the website. When searching a website that was data focussed (e.g. HDR UK) concept 1 became redundant, therefore the search focussed on concept 2. Where few results were returned, multiple forms of key terms like "data sharing" and "linked data" were used; where a very high numbers of results were returned (e.g. via gov.uk) we combined additional terms using 'AND' as a means of narrowing the focus.

Searches were limited to case studies from the last 5 years (since 2016), but with a post-2018 preference (i.e. inception of GDPR). We chose a pragmatic stop-search point of 100 eligible case studies being identified.

Phase 2: Study selection

Inclusion and exclusion criteria were applied (Table S1.1) with a pre-defined limit of 100 eligible case studies, reviewed by the SSC and SMG to decide on up to 30 for data extraction.

Phase 3: Data extraction

Details of included case studies were extracted into an Excel spreadsheet. Data for extraction included: (i) data sources used, including if it was a single, bespoke or existing linked dataset; (ii) specified 'data controller' and 'data processor'; (iii) any legal or IG frameworks / considerations specifically described; (iv) any described difficulties with obtaining or using the data; (v) examples of presenting routine data in novel /interesting/ useful / transparent ways. Initial data extraction was conducted by AS and MC, with further checks for completeness and accuracy conducted by TS and MF.

Phase 4: Contacting project leads for missing data

Where data was limited/missing, we contacted project leads (if they could be identified) or associated organisations via email. Where emails "bounced back", we attempted alternative contacts (e.g. other named project team members). In addition, we put a call out to the Association of Directors of Public Health via one of our stakeholders, which went in the Association's newsletter.

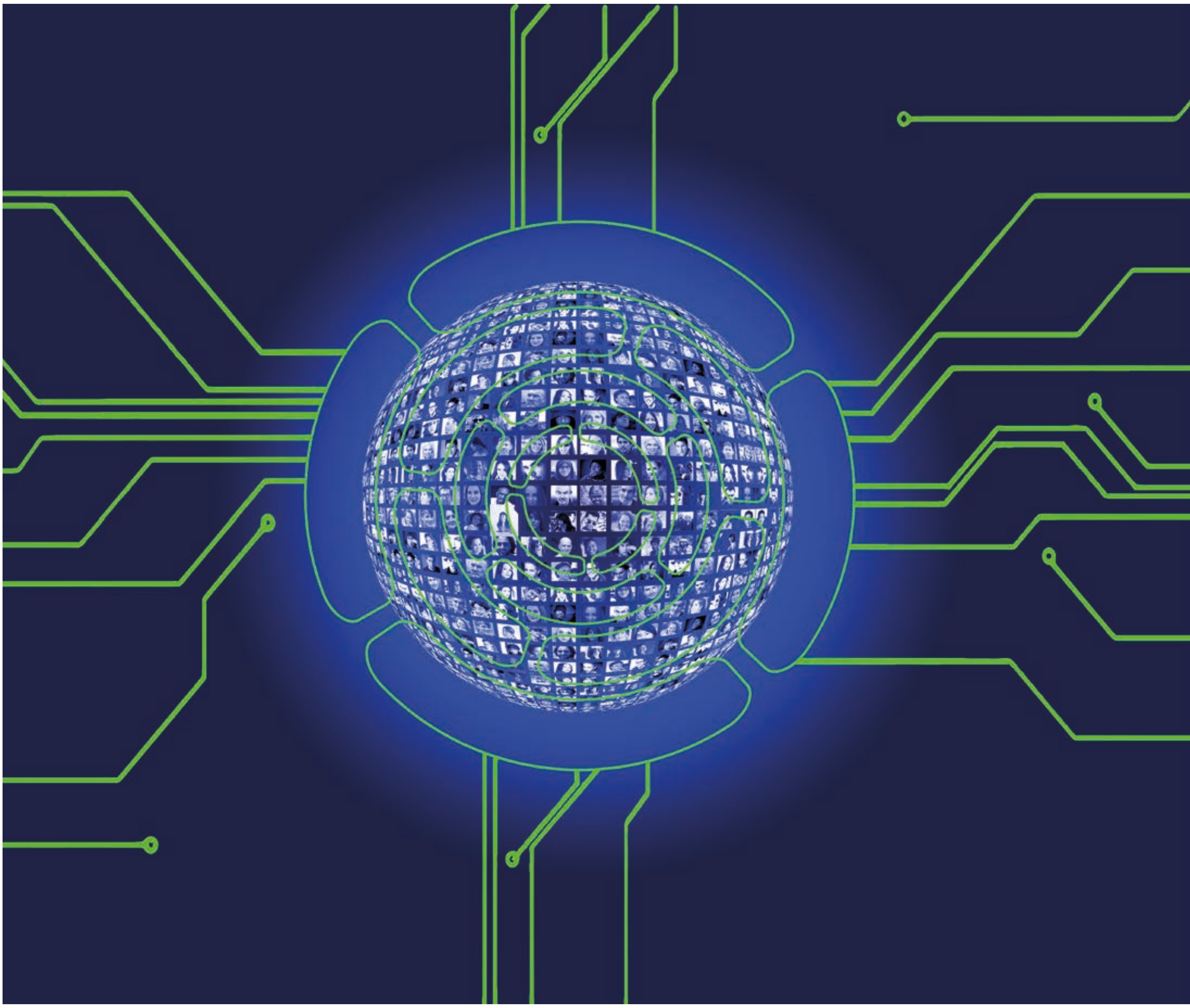


Table S.1: Inclusion and exclusion criteria

Inclusion	Exclusion
Local Authority based in England	Does not cover data from England
Uses routine data from at least one named source	Does not report the routine data source(s)
Focus: health, education, crime, or transport sector	Alternative sector to those of interest
Post-2016*	Pre-2016*
Inclusion	Exclusion

*Pre-2016 reports of case studies were included where the project described was still ongoing.

Table S1.2: General grey literature sources searched

Source	URL
HEALTH AND SOCIAL CARE	
HDRUK Innovation Gateway	www.healthdatagateway.org
Understanding Patient Data (Wellcome Trust)	https://understandingpatientdata.org.uk/case-studies
Better Care Fund (NHS England)	www.england.nhs.uk/ourwork/part-rel/transformation-fund/better-care-fund/
NHS England	www.england.nhs.uk/
NICE Evidence Search	www.evidence.nhs.uk/
NHSX	www.nhsx.nhs.uk/
Department of Health	www.gov.uk/government/organisations/department-of-health-and-social-care
Royal College of General Practitioners	www.rcgp.org.uk/
Health Education England	www.hee.nhs.uk/
House of Commons Library	https://commonslibrary.parliament.uk/
The Health Foundation	www.health.org.uk/
LOCAL GOVERNMENT	
Local Government Association (Case Studies)	Case studies | Local Government Association
EDUCATION	
Department for Education	www.gov.uk/government/organisations/department-for-education
Ofsted	www.gov.uk/government/organisations/ofsted
National Education Union	https://neu.org.uk/
CRIME	
Home Office	www.gov.uk/government/organisations/home-office
TRANSPORT	
British Transport Police	www.btp.police.uk/
Department for Transport	www.gov.uk/government/organisations/department-for-transport
Driver & Vehicle Licensing Agency	www.gov.uk/government/organisations/driver-and-vehicle-licensing-agency
National Highways	www.gov.uk/government/organisations/national-highways
ENVIRONMENT	
Environment Agency	www.gov.uk/government/organisations/environment-agency
Department for Environment Food & Rural Affairs	www.gov.uk/government/organisations/department-for-environment-food-rural-affairs
OTHER SOURCES	
Nesta	www.nesta.org.uk/
Centre of Excellence for Information Sharing	https://informationsharing.org.uk/
Commissioning Alliance	www.commissioningalliance.co.uk/
Information Commissioner's Office	https://ico.org.uk/

Table S1.3: Specific grey literature sources searched

Source	URL
Greater Manchester Combined Authority	https://www.greatermanchester-ca.gov.uk/
Connected Yorkshire	https://www.bradfordresearch.nhs.uk/our-research-teams/connected-bradford/
(Bradford Institute for Health Research)	https://imperialcollegehealthpartners.com/discover-now/
Discover-NOW (Imperial College Health Partners)	https://imperialcollegehealthpartners.com/discover-now/
Better use of data (Local Government Association)	https://www.local.gov.uk/our-support/research-and-data/data-and-transparency/better-use-data
Local Government Use of Data During the Pandemic (Centre for Data Ethics and Innovation)	https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/968515/Local_government_use_of_data_during_the_pandemic.pdf
COVID-19 Places Economic Recovery Index (CoPERI) (University of Sheffield)	Information Sheet via email, for further information see: https://www.sheffield.ac.uk/news/covid-19-pandemic-has-widened-gap-between-rich-and-poor-and-its-not-finished-yet
Joint Strategic Needs Assessments for Yorkshire and Derbyshire	https://observatory.derbyshire.gov.uk/jsna/ https://www.datanorthyorkshire.org/JSNA/JSNA (& other JSNAs at more local level e.g. https://www.teamdoncaster.org.uk/jsna https://www.calderdale.gov.uk/v2/residents/health-and-social-care/joint-strategic-needs-assessment-jsna)
Safe and Well Wakefield (Wakefield JSNA)	http://www.wakefieldjsna.co.uk/safe-and-well-wakefield/
Greater Manchester Violence Reduction Unit	https://gmvru.co.uk/

Table S1.4. Search terms

Concept 1: data processes	Concept 2: types of data	Concept 3: geographical
"data sharing", "linked data/ data linkage" "data controller", "information sharing", "information governance", "GDPR"	"Routine data", "census data", "routinely collected data", "public health data", "personal data", "service activity data", "health and social care data", "de-identified data"	England UK United Kingdom Great Britain

Table S1.5: Study Meeting Group (SMG) members and affiliations

Name	Organisation
Matthew Franklin (MF)	University of Sheffield
Anthea Sutton (AS)	University of Sheffield
Mark Clowes (MC)	University of Sheffield
Tony Stone (TS)	University of Sheffield
Suzanne Mason (SM)	University of Sheffield
Monica Jones (MJ)	University of Leeds
Susan Baxter (SB)	University of Sheffield
Annette Haywood (AH)	University of Sheffield
Sebastian Hinde (SH)	University of York
Daniel Howdon (DH)	University of Leeds
James Lomas (JL)	University of York
Original: Louise Brewins (LB) **Successor: Christopher Gibbons (CG)**	Sheffield City Council
Original: Jennifer Saunders (JS) **Successor: Philip Truby (PT)**	City of York Council
Michelle Horspool (MH)	Sheffield CCG

Table S1.6: Study Steering Committee (SSC) members and affiliations

Name	Organisation
Steven Senior (SS) – Chair	Health Education England (HEE)
Gerry Richardson (GR) – Deputy Chair	University of York
Katherine Brown (KB)	University of Hertfordshire
William Whittaker (WW)	University of Manchester
Emily Tweed (ET)	Glasgow University
Shane Mullen (ShM)	Local Authority Research Links (LARk) Wakefield
Vanessa Powell-Hoyland (VPH)	Doncaster Council
Barbara Coyle (BC)	Public Health England (PHE)
Abbygail Jaccard (AJ)	Public Health England (PHE)
Kamil Sterniczuk (KS)	PPI Co-Ap

APPENDIX S2: WP3 WORKSHOP SUPPLEMENTARY METHODS

Ethical considerations

The study received approval from the University Ethics Committee, and was also approved via the Health Research Approval process, and Clinical Governance process for each of the three sites. Information sheets and consent forms were emailed to potential participants prior to data collection; before each online workshop or interview, the consent form was screen shared. Each consent question was read aloud and anyone who did not consent was requested to close their web-browser and leave the session.

Research design

The COVID-19 pandemic and associated social restrictions meant online workshops and interviews were used to collect qualitative data; Table 1 provides an overview of the workshops' and interviews' phases and groups which were planned to be cyclical and iterative in order that findings from each session informed discussion at subsequent sessions. Due to poor attendance of Group 1 during Phase 1, the associated Phase 2 workshop was replaced with individual interviews to aid increase participation.

During study planning and development, we determined that the area of falls prevention would be a useful case study focus for the workshops, as stakeholders reported that it was an important issue to both the NHS and LA. This topic area was used to focus discussion (particularly with Group 1), although much discussion related to data sharing between LAs and NHS more broadly.

Participant selection

Participants were sought for Groups 1-3 from two LAs and two CCG within Sheffield and York, England; however, one York-based CCG withdrew from the study citing COVID-related capacity constraints. Additionally, project co-applicants from the Universities of Sheffield, York, and Leeds participated.

Within the LA and CCG organisations, we sought relevant individuals to approach using our co-applicant contacts and knowledge of their organisations. For each group, we invited representatives with similar roles in each organisation using a 'snowballing' technique (i.e. those invited could invite others with relevant knowledge or experience); we did not have a target sample size or eligibility restrictions post-invite.

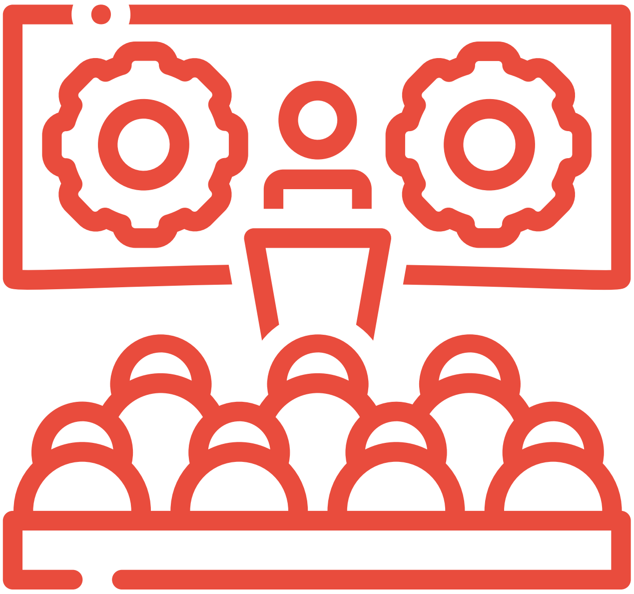
For the public workshops, our public co-applicant and public advisory group aided draft and distribution of an advertising flyer via their networks. We also advertised on the People in Research website, and used existing PPI databases and student lists. Based on responses, we purposively selected potential participants to achieve a range of age, gender, ethnicity, geographical local, and views/interest in data sharing.

Data collection

Phase One workshops consisted of introductions and study overview, followed by open discussion documented using live edited PowerPoint slides. From Workshop Two onwards and for the interviews, summaries of previous workshops including key discussions points were presented to stimulate discussions. Workshops were scheduled for 1.5 hours and interviews lasted 45-60 minutes, both recorded using a handheld encrypted data recorder.

Data analysis

Based on the recordings and notes taken during the workshops/interviews, documents were developed by SB and AH containing both researcher notes and verbatim participant quotes which were used to identify key points/themes. These points were discussed at SMG and SSC meetings, and subsequent workshops/interviews as part of an iterative, further discussion and refinement process.



APPENDIX S3: WP4 HEALTH ECONOMICS SUPPLEMENTARY RESULTS

The role of different decision-making frameworks and criteria

To conduct a full EE, analysts require a decision-making framework to judge and quantify both costs and outcomes of relevance, and criteria to determine the optimal decision. While other frameworks exist that only focus on costs or outcomes (not both), these are generally considered 'partial' evaluations: for example, budget impact analyses (BIA), involving the consideration only of costs [7, 61]. For descriptive purposes we focus on three potentially local-decision-maker-relevant frameworks: health technology assessment (HTA), multi-criteria decision analysis (MCDA), and programme budgeting and marginal analysis (PBMA).

Health technology assessment (HTA)

HTA-associated decision-making frameworks and criteria are most commonly associated with reimbursement agencies and related processes, such as the focus in NICE's reference case on comparison of the relevant ICER with some threshold value or range [49]. Such methods are not commonly used nor fully accepted by local decision-makers to guide their commissioning cycle [41, 62, 63]. HTA frameworks can incorporate a range of maximisation problem conceptualisations beyond QALYs, whereby outcomes could be both natural units (e.g. life years) or monetary values [7, 64]. Fundamentally, however, approaches associated with HTA processes tend to seek to explicitly maximise a defined outcome subject to some budgetary constraint. As an approximation to this, use is commonly made of ICERs (and their comparison to some threshold value or range), or return-on-investment ratios, where some new candidate programme is compared to existing programmes that could be defunded. The use of such approximations, however, becomes less appropriate when new candidate programmes would take up a large proportion of the total budget [46, 47], or when substantial uncertainty exists around ICER estimates [5].

Multi-criteria decision analysis (MCDA)

MCDA allows for a range of outcomes and costs to be accounted for within the same framework which are decided upon through stakeholder engagement, whereby the decision problem is subject to a range of criteria for consideration. Although it's possible to compare costs to multiple outcomes within HTA-associated EE frameworks (e.g. produce multiple ICERs based on various outcomes), weighting and trading-off between the outcomes and associated criterion (e.g. trading-off maximising health relative to social functioning) are not known but could be deliberated within a MCDA framework. Guidance for MCDA has been developed with a 8-step guide focussing on determining, weighting, and assessing the criteria by which any results are compared [65, 66]; these 8-steps are: defining the decision problem; selecting and structuring criteria; measuring performance; scoring alternatives; weighting criteria; calculating aggregate scores; dealing with uncertainty; interpretation and reporting results. Overall, permitting and trading-off multiple criteria is the perceived benefit, but also limitation of MCDA; there is an argument that such subjective preference-weighting requires more structure to avoid a 'town hall' (e.g. whoever shouts the loudest will win) approach to weighting/trading-off criteria for consideration.

Programme budgeting and marginal analysis (PBMA)

PBMA is a MCDA example, with a specific focus on reviewing resources allocated to specific programmes with subsequent assessment of added/forgone benefits and costs from alternative programme(s) and associated budgets. Similar to MCDA, PBMA has 8-steps [5]: choose a set of meaningful programmes; identify current activity and expenditure in those programmes; think of improvement; weigh up incremental costs and incremental benefits and prioritise a list; consult widely; decide on changes; effect the changes; evaluate progress. These steps reflect the commissioning cycle: strategic planning, procuring services, then monitoring and evaluation. Thus, it has been suggested to aid with investment and disinvestment decisions. The consideration of disinvestment and accounting for budgetary restrictions for specific programmes is an important consideration for local decision makers, thus making the PBMA approach a pertinent consideration. A key limitation is that PBMA does not focus on any specific or range of criterion (e.g. as within HTA and MCDA); thus, the scope of the decision-problem both in term of relevant outcomes and associated costs (and budgets) can be difficult to conceptualise and then operationalise within this approach.