MOTT MACDONALD

Primary Care Professionals' Attitudes to Data Use

Final Report

February 2022

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Conditions which underpinned these views:

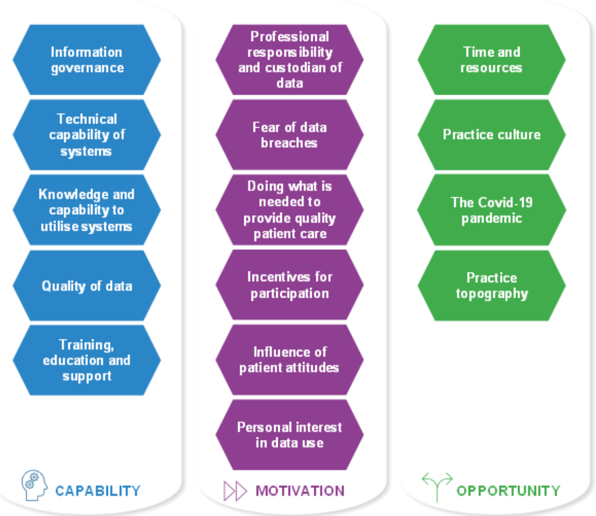
Being assured….

- of the **purpose** for which data is being used
- as to who will have **access** to the data
- as to who the **beneficiaries** of the use of data will be
- that data will be appropriately **safeguarded**

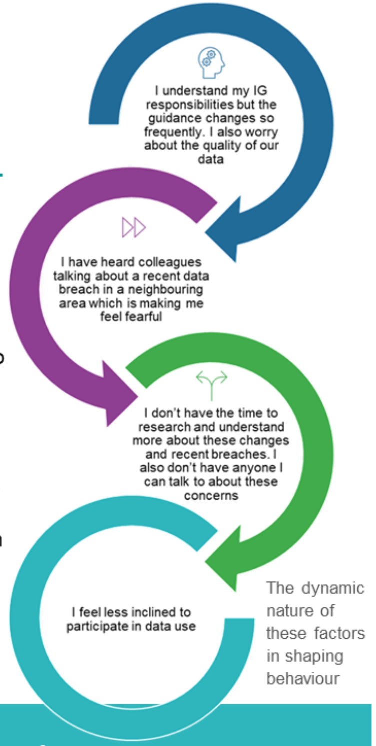
2. What informs these attitudes?

There are a range of factors which influence of the attitudes of primary care professionals to use and share data, affecting their capability, motivation and opportunity to do so. It is the combined influence of these factors which is shaping behaviours on data use.

- There is a **strong sense of responsibility** for safeguarding patient data, alongside a view that data use for care and care coordination, planning and research is needed to provide the **best quality patient care** possible.
- For GPs, and particularly those GPs who may be partners, the **contractual and legal responsibilities of information governance and data protection** strongly informed attitudes.
- Whilst nearly all professionals understand these information governance requirements, there are challenges in **navigating these and accessing support**, which can ultimately **generate fear**.
- **Time and resources** are a limiting factor for data use within primary care.
- Primary care professionals and patients can have an **unconscious influence** on each other's attitudes to data sharing.



- **Practice culture** is important in shaping attitudes and behaviours. **Clinical leadership** supported by effective **practice management** enable professionals to feel empowered to use data. The Practice or PCN **data eco-system** and **previous involvement** in data driven projects also has influence in building understanding and trust.
- Those primary care professionals with an interest in data feel more comfortable in sharing data for research purposes. For some, data use and research appeared to be considered as **distinct from a primary care professional's core role**.
- There has been much commonality in the factors described by different roles working within primary care, although those **working in primary care additional roles have described less anxiety** towards information governance responsibilities.



The dynamic nature of these factors in shaping behaviour

3. Overcoming barriers:

Interventions which could help to overcome the challenges expressed and engender trust in the use of health data include:

- ✓ Education and training
- ✓ Enablement activities
- ✓ Improved communication

For primary care professionals to be engaged and empowered in using data, it is important that they are **consulted and considered** in the design and implementation of data related initiatives.

The findings from this research have been used to develop a **checklist** for those planning or implementing a data related initiative in primary care. This practical tool will allow users to proactively and systematically assess the range of factors which will shape primary care professional's behaviours to the initiative.

Executive summary

Introduction and scope

Primary care is the backbone of the healthcare system and for most patients, it is the 'face' of healthcare providing first-line access to advice and treatment. For a successful integrated and person-centred approach to healthcare, the use of data is instrumental - not only in providing individual care and coordination but enabling better planning and developments in the systems which support individual care.

The primary care data ecosystem continues to evolve, with the COVID-19 pandemic highlighting the importance of data use and sharing across both patients and professionals and with system providers seeking to enhance the technical capability and integration of systems. The publication of the Data Saves Lives strategy, alongside developments such as GPDPR and the accelerated programme for access to full historical GP records continue to push progress in this area.

To enable a greater understanding of primary care professionals' response to this, Understanding Patient Data (UPD), part of the Wellcome Trust, and the Royal College of General Practitioners (RCGP) commissioned this study to understand the views and attitudes of primary health care professionals on data use.

This study has therefore explored:

- Primary care health professionals' views on the use of health data
- Enablers and barriers to the uptake of and advocacy for data use in individual care and coordination, planning and research
- What interventions could help to overcome the challenges expressed and engender trust in the use of health data.

In doing so, we contributed to testing the validity of the following hypothesis: *Identifying positive benefits, and minimising perceived risks, increases primary care health professionals' willingness to advocate for and support the use of high-quality health data.*

Navigating this report

This report begins with an executive summary and a one page summary of key findings. Within the main body of the report, the highlights from key chapters have also been summarised, allowing the reader to quickly digest key messages arising from this study.

Methodology

The framework for this engagement is based on Michie's COM-B model[1] to unpick the capabilities, motivations and opportunities that shape attitudes and behaviours to data use.

The methodology has comprised three phases of engagement, as illustrated in Figure 0.1.

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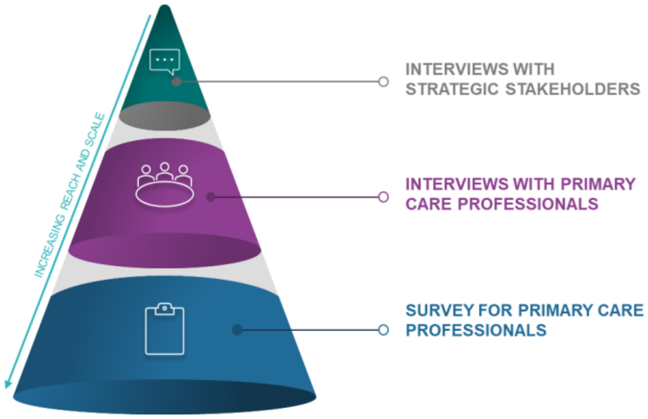
[1] Michie, S., M. M. v. Stralen and R. West (2011). "The behaviour change wheel: A new method for characterising and designing behaviour change interventions." Implementation Science 6(42): 11

Figure 0.1: Approach to engagement



Interviews were undertaken with 37 primary care stakeholders between April 2021 – January 2022. To test themes gathered from the literature review and interviews, an online survey was developed to generate the scale of findings. The survey was shared directly to known stakeholders and via active forums which reach those working in primary care. Thematic analyses of the above activities were undertaken in line with the established framework and COM-B model[2]. A virtual roundtable was also utilised to present and validate emerging findings with an audience of six strategic stakeholders including GPs, GPs working in research, a practice manager and representation from NHS Digital.

Primary care health professionals’ views on the use of health data

Whilst perhaps not surprising, this study has identified that primary care professionals who responded to the survey felt most comfortable sharing data across their practice and PCN. The appetite for sharing data reduced as the data moved further away from the practice to the ICS, wider NHS and more broadly. Similar trends were seen in attitudes regardless of the purpose for which this data was being shared or used (care and coordination, planning and research), although a greater proportion of respondents were comfortable with data being shared more widely for research purposes. Qualitative comments highlighted some of the conditions which were important to this such as the appropriate anonymisation of data and information governance processes which facilitate the protection of this data.

Factors which influenced attitudes to data use

There are a range of factors which influence the attitudes of primary care professionals to use and share data. Using Michie’s COM-B model[3], these factors have been grouped within the conditions of capability, motivation and opportunity, recognising that it is these three conditions which shape behaviours. Each factor is a continuum, acting as an enabler or barrier depending on where each individual sits on that spectrum. Each of the factors outlined in Figure 0.2 is important in its own right but does not exist in isolation. It is their combined influence which is ultimately shaping behaviours around data use.

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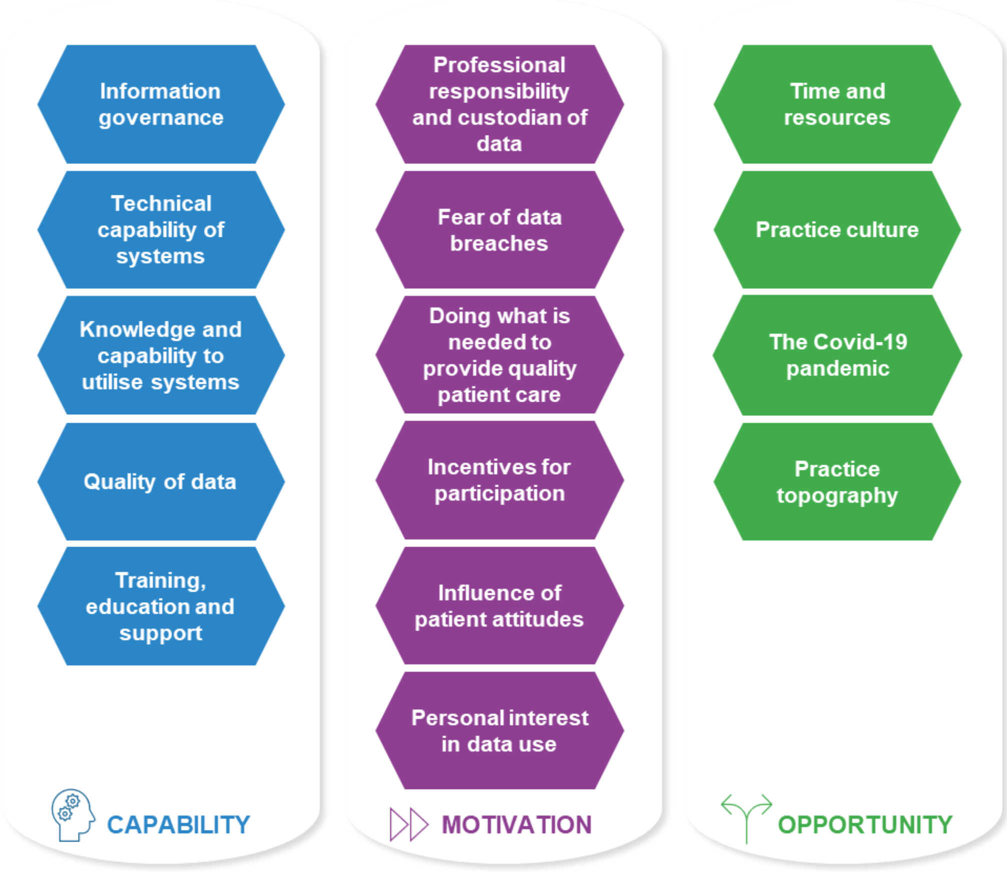
[2] Gale, N. K., Heath, G., Cameron, E., Rashid, S., & Redwood, S. (2013). Using the framework method for the analysis of qualitative data in multi-disciplinary health research. BMC medical research methodology, 13, 117. https://doi.org/10.1186/1471-2288-13-11

[3] Michie, S., M. M. v. Stralen and R. West (2011). "The behaviour change wheel: A new method for characterising and designing behaviour change interventions." Implementation Science 6(42): 11

Figure 0.2: Factors influencing attitudes to data use



For GPs, and particularly those GPs who may be partners, the contractual and legal responsibilities of information governance and data protection were most commonly mentioned, alongside the professional responsibilities as a custodian of patient data. Whilst our survey results suggest that nearly all professionals understand these requirements, processes and responsibilities, these GP stakeholders have described to us the challenges in navigating these, accessing support where this is needed and the fear that this can generate. From qualitative engagement in this study, a picture was painted where GP partners sit at the nucleus of the practice as the data controller. The further away that primary care professionals sit from the practice, the less anxiety is felt towards data sharing.

Whilst professionals have a strong sense of responsibility for the safeguarding of patient data, at times through our engagement, there has been a sense that data use or research is distinct from a primary care professional’s core role. Whilst some GPs have described a reliance on their administration teams for good coding, others have described the importance of every professional having a responsibility for data quality and record curation.

Time and resources are clearly a limiting factor within primary care, but practice culture is also important in shaping attitudes and behaviours. Clinical leadership supported by practice management and an effective administration team enable professionals to feel empowered to use, interrogate and share data, participate in research and improvement studies and to confidently talk to their patients about how their data is used and safeguarded. It was also considered that a practice’s own data eco-system and the extent to which they had been involved in data driven projects has some influence. Professionals reflected that where practices have been on a journey to build understanding of how data is extracted, anonymised and used safely and for what benefit, trust is built and they are more likely to become involved in data driven projects in the future.

Whilst data protection officers were mentioned by some stakeholders as a source of support, their visibility and the level of support they provide is reported to be variable.

The influence that primary care professionals and patients have on each other's attitudes to data sharing is an interesting finding. Whilst there is a spectrum of views from patients about how their data is used, patients were described to rarely question data sharing with primary care professionals. Stakeholders did describe the unconscious influence that primary care professionals may have on patients, for example in sharing opt out forms as part of usual practice and without explanation.

Whilst there has been much commonality in the factors described by different roles working within primary care, variation has been evident where those working in primary care additional roles[4] described less anxiety towards information governance responsibilities. This may be influenced by the nature of their work which means they already utilise different clinical systems depending on the location in which they are working, which may also be across a number of practices, a PCN or ICS. This is in contrast to the contractual obligations held by GPs which influence their attitudes in this area. Those working within these additional roles were also able to provide interesting reflections on the importance of practice culture, bringing their experiences of working across practices and PCNs.

In Figure 0.3 below we have outlined two scenarios about how these factors could manifest in practice. Whilst we recognise that these are a simplification, it provides an insight as to how these factors come together to influence the attitudes of primary care professionals.

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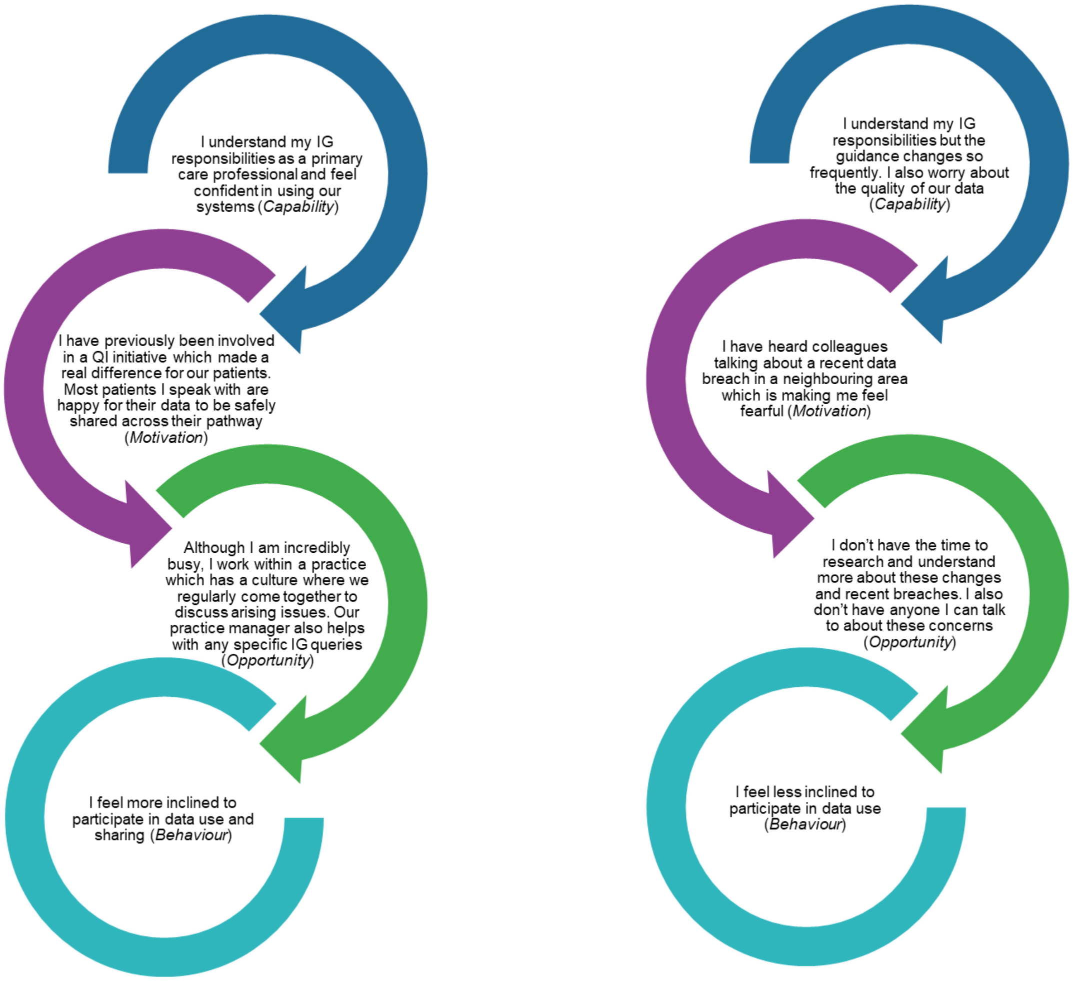
[4] The Additional Roles Reimbursement Scheme (ARRS) allows PCNs to appoint to advanced practitioners in primary care. This spans a range of roles including, but not limited to clinical pharmacists, community paramedics, social prescribing link workers, care co-ordinators and health and wellbeing coaches.

Figure 0.3: The dynamic nature of these factors



I understand my IG responsibilities as a primary care professional and feel confident in using our systems (*Capability*)

I have previously been involved in a QI initiative which made a real difference for our patients. Most patients I speak with are happy for their data to be safely shared across their pathway (*Motivation*)

Although I am incredibly busy, I work within a practice which has a culture where we regularly come together to discuss arising issues. Our practice manager also helps with any specific IG queries (*Opportunity*)

I feel more inclined to participate in data use and sharing (*Behaviour*)

I understand my IG responsibilities but the guidance changes so frequently. I also worry about the quality of our data (*Capability*)

I have heard colleagues talking about a recent data breach in a neighbouring area which is making me feel fearful (*Motivation*)

I don't have the time to research and understand more about these changes and recent breaches. I also don't have anyone I can talk to about these concerns (*Opportunity*)

I feel less inclined to participate in data use (*Behaviour*)

Testing the hypothesis

This study has also contributed to testing the validity of the following hypothesis: *Identifying positive benefits, and minimising perceived risks, increases primary care health professionals' willingness to advocate for and support the use of high-quality health data.* Key findings from the engagement of this study in response to this hypothesis are as follows:

- A common theme from many working across primary care was that data use is needed to provide the best quality patient care possible; both in terms of care and care coordination but also for research and planning for future treatment and services. Benefits include the improved quality and safety of patient care, alongside the efficiencies achieved by reducing fragmentation and duplication. The useful outputs which can go on to shape patient care, local planning and research are also important incentives for participation. These are motivating behaviour conditions.
- Across the spectrum of primary care health professionals engaged with as a part of this study, there is a strong sense of responsibility for the safeguarding of patient data. Whilst our survey results suggest that nearly all professionals understand the requirements, processes and responsibilities associated with their role, GP stakeholders have described to us the challenges in navigating these, accessing support where this is needed and the fear that this

can generate. These risks are associated with capability, motivation and opportunity factors. The following conditions are considered to minimise these perceived risks:

  - Being assured of the purpose for which data is being used, including to advance quality of care or treatment
  - Being assured as to who will have access to the data
  - Being assured as to who the beneficiaries of the use of data will be
  - Being assured that data will be appropriately safeguarded. For research and planning this may include de-personalising or anonymising data, gaining consent and utilising TREs.
  - Being assured that appropriate data sharing protocols and agreements are in place.
- Whilst the majority of survey respondents agreed they were comfortable sharing data across the practice for care and coordination and research purposes, this level of comfort decreased the more widely the data is to be shared. A greater proportion of respondents were comfortable with sharing data for research purposes across the PCN, ICS and more widely within the NHS, compared to sharing data for care and coordination. This is likely to be due to the conditions in which the data is being shared, including the anonymisation of data where appropriate.
- Nearly all participants in this study have advocated for the use of data but we have heard many describe a 'trade off' between benefit and risk.

Overcoming barriers

Understanding these conditions and factors that shape attitudes and behaviours can enable programmes of change to better plan, communicate and consult with primary care stakeholders. Interventions which could help to overcome the challenges expressed and engender trust in the use of health data include:

- Enhanced or increased **education and training**, which was commonly described to achieve:
  - Improved clarity on information governance processes
  - Improved skills to maximise existing systems and processes
  - Improved quality of data coding and record curation
  - Improved analytical skills.
- **Enablement activities** to address some of these barriers were also described. Examples of these included:
  - Easier access and visible support from expert resources such Data Protection Officers or Caldicott Guardians
  - Sample templates for data sharing agreements and Data Protection Impact Assessments (DPIAs) that could be adapted
  - Support to further enable clinical leaders to foster trust in data use and some of the issues described in this study
  - Engagement and peer learning with professionals in practices with a mature and successful data ecosystem.
- To build motivation, **improved communication** with the public, patients and primary care workforce were considered to be important

It is recognised that work to progress some of these opportunities is already underway as part of the implementation of *Data Saves Lives*, the *Long Term Plan* and as part of local work which is being undertaken in primary care. For example, strengthened communication with health professionals and the public about GPDPR is an important priority before the data extraction framework is embedded. DHSC also describe commitments to simplify information governance arrangements, improve training and establish a one-stop shop for guidance and assistance.

For primary care professionals to be engaged and empowered in using data, it is important that they are consulted and considered in the design and implementation of data-related initiatives. The findings from this research have been used to develop a checklist for those planning or implementing a data-related initiative in primary care. This practical tool will allow users to proactively and systematically assess the range of factors which will shape primary care professionals’ behaviours to the initiative. The checklist:

- Is structured around the conditions of capability, motivation and opportunity and the factors identified through this study
- Provides an insight into the questions that a primary care professional may be considering
- Outlines a set of questions for programme stakeholders to proactively consider as part of the planning and implementation of their initiative.

The checklist is provided overleaf.

Condition	Questions a primary care professional may have	Checklist for programme stakeholders
Capability	Do I understand and am I comfortable with the information governance implications of the initiative and any actions that are required of me? Does my clinical system have the capability to do what is being asked? If additional functionality is being developed, am I able to use this? Where can I access support or training?	1. What will be the information governance implications of the initiative for primary care professionals? Have these been considered and discussed with relevant primary care and legal professionals? 2. How will these implications be communicated to primary care professionals? 3. Are there tools you can supply to help professionals navigate these implications (such as user-friendly data protection impact assessment templates for example)? 4. Do existing systems have the capability to fulfil the requirements of the initiative or is additional functionality required? 5. Are there any changes required in the ways of working? 6. How will the above be communicated with primary care professionals? 7. Is additional training required? Who will provide this and how can professionals access this? 8. Where can primary care professionals access support if needed?
Motivation	Do I understand the purpose and need for the initiative and what the benefits will be? Do my colleagues working in primary care also understand this and do they have any concerns? How are my patients being made aware of this initiative? Are there any implications for the practice from this communication with patients?	9. Have the benefits of the initiative been articulated? 10. Have these been considered and discussed with relevant primary care professionals to ensure these benefits are comprehensive and that there is ownership from the primary care community? 11. Do primary care professionals understand the initiative, it's purpose, scope, who the data will be shared with, how it will be treated and how it will be secured? 12. Have any concerns been raised and discussed with primary care professionals? 13. What opportunities are there for practices or primary care professionals to provide ongoing feedback about the initiative? 14. How have the public been involved in this development of this initiative and are their concerns understood? Has a public facing communication plan been developed for this initiative? 15. Has the timing of the implementation of this communication plan been considered to ensure that primary care professionals and practices are prepared and able to respond to arising queries?
Opportunity	What will be the resource implications for my practice or PCN? How does this initiative align with other developments that I know are underway, both in terms of scope and timing? Is anyone leading this work locally so that we can understand more about lessons learnt?	16. Have the resource implications of the initiative on primary care been considered in consultation with primary care professionals? 17. Is there the opportunity to provide support to mitigate against resource implications? 18. Are there any other initiatives or primary care priorities which need to be considered in the planning and implementation of this initiative and its timing? 19. Are clinical leaders across ICS, PCN and practices aware and engaged in the initiative? How best could they influence local stakeholders? 20. Could peer learning be utilised in the roll out of this initiative?

1 Health data in primary care

Health services globally are evolving rapidly and, over the coming years, some of the most wide-ranging changes are expected to occur in primary care. Primary care is the backbone of the healthcare system and for most patients, it is the 'face' of healthcare providing first-line access to advice and treatment.

Primary care accounts for the largest proportion of patient contacts within the NHS, at around 300 million per year in general practice alone[5]. It is having to adapt at pace to manage the increasing challenges of an ageing and growing population. As well as delivering 'business as usual', primary care needs innovation, redesign for greater sustainability and a more integrated, personalised, and person-centred care approach. In addition, there is growing evidence that community building and working with local community 'assets' (often in partnership with local authorities and the voluntary sector) is essential to achieving better population health outcomes, improved self-management of long-term conditions and reducing pressures on healthcare systems and workforce[6].

Given the global 'left shift' in health services which means providing care out of hospital, there is a greater influence of prevention strategies, including digital health, vaccination, and lifestyle promotion. Whilst prevention is everybody's business, as the first point of contact for the majority of people, primary care is a key setting for improving local population health by reducing the future burden of disease caused by avoidable risk factors. Furthermore, many of the inequalities in health status and outcomes derive from the disproportionate distribution of risk factors in local communities.

Traditionally, the role of the General Practitioner focused on 'family-centred' care in a model which places the GP as a core and consistent figure within families and communities, whilst being supported by nurses and practice-based staff. However, the increasing demand and changing working patterns of GPs has resulted in a change to the traditional model; whilst the GP remains the cornerstone of primary care, a greater emphasis has been placed on an increasingly multi-professional team.

Patients rely on primary care to collaborate and coordinate, acting as a bridge into the wider health and social care system. More recently, the formation of primary care networks (PCNs) in England have brought flexibility into ways of working but this places even greater emphasis on the need for joined up care. The figure below depicts the complexities of the system, not only from PCNs but out of hours services through extended access hubs and NHS111. The need for a joined-up service is just as important in the wider health and care system; patient information originating from primary care is required across urgent care, planned care and more widely through the Integrated Care System (ICS). An overview schematic of the complex system can be found in Figure 1.1.

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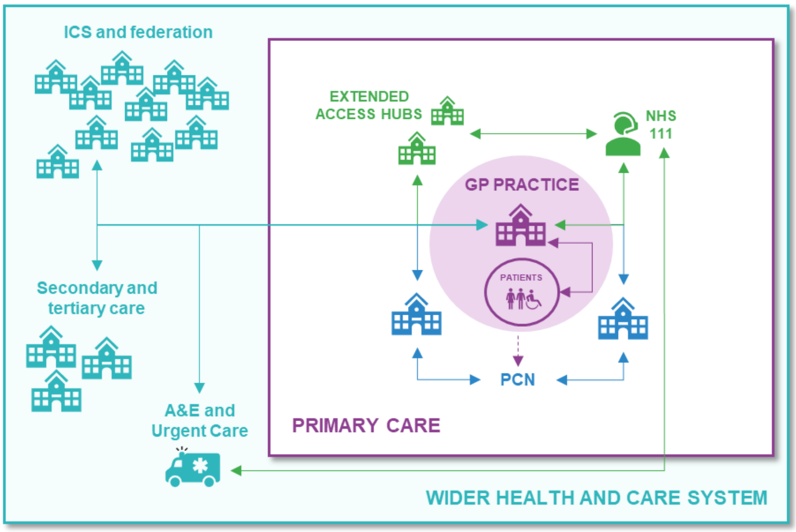
[5] gp-partnership-review-final-report.pdf (publishing.service.gov.uk)

[6] At the heart of health: Realising the value of people and communities | Nesta

Figure 1.1: Primary care as the central host for the health system



1.1 Data use in Primary Care

For a successful integrated approach, the use of data is instrumental - not only in providing individual care and coordination but enabling better planning and developments in the systems which support individual care.

As standard, patient information is held on an electronic health record. This is predominantly on a record supported by one of the key companies in this field; EMIS Web (EMIS), SystmOne (TPP), Vision (InPractice) and Evolution (Microtest)[7]. Within these systems, information is recorded on a patient's personal details, medical history (i.e. vaccinations and test results) and healthcare activity (i.e. appointment and referral letters).

More recently, there has been a rise in the uptake of additional platforms which link into the clinical record systems described above. Enabling platforms for remote consultations and workflow management such as AskMyGP and AccuRx have broadened the capabilities of digital primary care.

For each consultation with a healthcare professional, a narrative is recorded in free-text format and usually guided by a number of headers using the HEOP format: history, examination, outcome and plan. Alongside this, a number of discrete categories are coded and linked to an agreed, standardised library of clinical terms. Recently, SNOMED CT[8] was the agreed clinical coding language for NHS England and includes detail beyond diagnoses that incorporates coding for symptoms and procedures[9]. Combining free-text and coding approaches to data entry supports the level of detail required for providing individual care with the ability to also provide a level of consistency within the data for large-scale analysis for planning and research.

Nevertheless, there are inherent challenges in the quality and completeness of the data inputs which are recorded on the primary care systems. For example, a recent COVID-19 study suggests that 26% of people do not have ethnicity information recorded about them within UK health records[10]. The significance of this should not be overlooked as accurate health records

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[7] GP Connect progress - NHS Digital

[8] SNOMED CT is a structured clinical vocabulary for use in an electronic health record.

[9] SNOMED CT - NHS Digital

[10] OpenSAFELY: Factors associated with COVID-19 related hospital deaths in adult NHS patients, 28 April 2020 - GOV.UK (www.gov.uk)

are a "necessary pre-requisite to addressing inequalities in health service usage and outcomes".[11]

Beyond this, there is a significant level of heterogeneity in how each PCN, practice or professional records information on the system. The variable quality and accuracy of coding is well-documented within the literature[12]. Examples of known challenges with coding include patients frequently attending with multiple presentations, a clinician unable to find an appropriate code for the presentation, codes being entered in error and the clinician relying on free-text data entry only[13].

In an effort to support improvements, recent work has developed tools to assess readability and structural accuracy of SNOMED CT coding[14]. Financial incentives are currently in place for accurate recording through the Quality and Outcomes Framework (QOF). However, this has not been without its controversy as concerns were raised that this may influence clinical decision-making and behaviours[15]. A 2016 review of QOF concluded for example that the universally high QOF achievement means that practices have little motivation to improve achievement further for existing indicators. It also reported that there was no evidence that QOF encourages any other aspect of primary care performance than those elements incentivised by the QOF and in particular, it does not reward holistic care, integrated care or patient-centred care and may divert practices from other aspects of providing high quality of primary care and from prioritising those patients with the greatest needs[16].

Moreover, there is a recognition that data use in primary care is generally fragmented and, instead, ambitions of the GP IT Futures programme aim to streamline approaches and provide safe, resilient and functionally rich clinical GP systems, which can safely and securely access and use primary care data in real-time. Given the complexities across the health system, as depicted in Figure 1.1, it is clear that the programme is seen as a welcomed system enabler to join up care i.e. with secondary care, across the ICS, PCN and within the practice. Improved integration of data will support the policy ambitions of greater multidisciplinary team working in primary care and enable preventative initiatives, such as social prescribing.

1.2 The policy landscape for data use in primary care

1.2.1 Relevant to healthcare

The central policies relating to data use in primary care are well-embedded and have remained significantly unchanged for many years. Data use has long been recognised as essential for providing direct care within the NHS. The united message following the 2013 Caldicott review, was that gaps in patient care should not be as a result of an inability to use data effectively. A direct quote states, *"the duty to share information can be as important as the duty to protect patient confidentiality".* The Health and Social Care Act 2015 was subsequently introduced into law; outlining a duty to share certain types of data (personal data and anonymised data) where it concerned facilitating the provision of care to a patient. However, the confidence of health professionals to use data is central and the Caldicott principles were set out in support, alongside a call for support from employers, regulators and professional bodies.

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[11] Completeness and usability of ethnicity data in UK-based primary care and hospital databases | Journal of Public Health | Oxford Academic (oup.com)

[12] Accuracy and completeness of electronic patient records in primary care | Family Practice | Oxford Academic (oup.com)

[13] Using primary care data for health research in England – an overview | RCP Journals

[14] Analysis of readability and structural accuracy in SNOMED CT | BMC Medical Informatics and Decision Making | Full Text (biomedcentral.com)

[15] Margaret McCartney: The great QOF experiment | The BMJ.

[16] Review-of-QOF-21st-December-2016.pdf (prucomm.ac.uk)

Patient choice is, of course, imperative in data use. Following a review by the National Data Guardian in 2016, it was suggested that a single opt-out model should be adopted across the health and care system in England[17]. As a result, a National Data Opt-Out was actioned to allow those who did not wish for their data to be used for research and planning purposes to withdraw their consent. In this case, anyone over the age of thirteen has the right to withdraw their information, with parents or guardians able to decide for those under the age of thirteen. There are a number of occasions where their opt-out choice can be overridden, this includes:

- When required by law
- When there is overriding public interest (for example, in public emergencies as seen in the COVID-19 pandemic)
- When information that can identify you is removed
- When there are specific exclusions (such as the census, National Cancer Patient Experience Survey and CQC NHS Patient Survey Programme).

In 2021, the draft *Data Saves Lives*: reshaping health and social care with data strategy[18] was published by the Department for Health and Social Care (DHSC). This acknowledges the challenges currently experienced by health professionals, describes progress to date and sets out a vison giving health and care professionals the data they need to provide the best possible care. The strategy is underpinned by the following priorities:

- To build understanding of how data is used and the potential for data-driven innovation, improving transparency so the public has control over how we are using their data
- To make appropriate data sharing the norm and not the exception across health, adult social care and public health, to provide the best care possible to the citizens we serve, and to support staff throughout the health and care system
- To build the right foundations – technical, legal, regulatory – to make that possible.

These priorities are to be achieved through:

- Simplifying information governance
- Creating a new duty to share
- Delivering shared records
- Reducing the data collection burden
- Harnessing safe and effective innovation.

The strategy also recognises that to deliver truly patient-centred care, people should have better access to their personal health and care data and understand exactly how it is used. Giving people confidence in how their data is used to improve patient and service user safety are key for this. In their response to the strategy[19], the National Data Guardian highlighted the importance of safeguarding patient confidentiality, reinforcing the importance of building public trust and ensuring that people understand how their data is used.

Since the COVID-19 pandemic, the importance of data use has become more evident. This has included the outputs of data use being showcased in the mainstream media and public health arena. The policy landscape surrounding this is therefore in a period of development. As described above, we expect to see a greater emphasis placed on policy and enabling features and interventions which advocate for data use in the immediate future.

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[17] Review of Data Security, Consent and Opt-Outs (publishing.service.gov.uk)

[18] Data saves lives: reshaping health and social care with data (draft) - GOV.UK (www.gov.uk)

[19] NDG_Data_Strategy_Response_v1.0 - 08.09.21.pdf (publishing.service.gov.uk)

1.2.2 Relevant to primary care

Since April 2019, individual GP practices have been able to establish or join Primary Care Networks. This has been supported through a DES (directed enhanced service), which provides funding for the provision of additional workforce and services that the PCN will be required to provide. To effectively operationalise, patient data must be accessible across the network. It is stipulated in the Primary Care Network Agreement that, before *"any personal data is shared between any members of the Network Agreement, the relevant members are required to enter into a data sharing agreement".* NHS England has set up templates[20] for data sharing agreements between constituent practices. Some networks have sought legal and professional advice to ensure compliance with current legislation.

Providing patients with access to their online records has been discussed for a number of years. This is included as part of the NHS Long Term Plan and agreed by NHS England and the British Medical Association (BMA) General Practitioners Committee in England. In September 2020, Matthew Gould, Chief Executive, NHSX declared a commitment to shared care records for professionals.[21] He noted that this would *"improve direct care for individual patients and service users and to underpin population health and effective system management".* The draft *Data Saves Lives* Strategy builds on this, committing to *"deliver comprehensive shared records, in line with the commitments in the NHS Long Term Plan so that authorised staff for other care partners can easily and appropriately access data regardless of where care is delivered (by 2024)".* It describes how this will *"focus first on linking general practice and hospital trusts, working towards comprehensive record sharing by 2024, in line with the NHS Long Term Plan and allowing people to make their own contributions into that shared care record".*

In tandem and to complement the strategy, Professor Ben Goldacre has also been commissioned to assess how health data for research and analysis can be used efficiently and safely[22]. The conclusions from this review are not yet available but are anticipated imminently.

Over the course of 2021, within primary care, a number of data driven programmes have received considerable discussion including GP Data for Planning and Research (GPDPR) and Accelerating Citizen's Access to GP Data. NHS Digital outlined a new framework for data extraction called the General Practice Data for Planning and Research (GPDPR) collection to improve how data is collected from practices for benefit of research and planning[23]. In response to considerable feedback, the initial timescales for the programme have been revised and further work is being undertaken in collaboration with a range of partners to strengthen the plan. This is focused on making the opt out process simpler, considering the implications the opt out process has on the administrative workload of practices, developing a practice Data Protection Impact Assessment (DPIA) template for practices, developing a Trusted Research Environment (TRE) with transparency as to who can access this data, as well as strengthening communication and engagement with patients and the healthcare system about GPDPR.

1.3 Systems and processes which enable data use in primary care

As illustrated by UPD in Figure 1.2, the term data use comprises a wide range of purposes and involves both the direct use of data as well as how this is shared securely across the health system.

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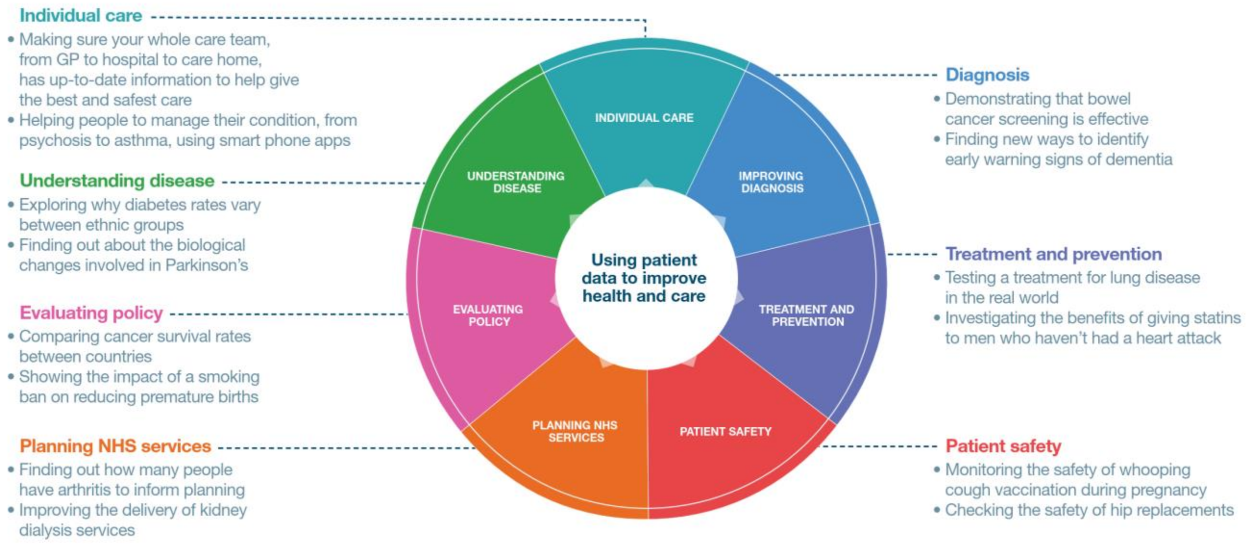
[20] NHS England » Network Contract Directed Enhanced Service data templates

[21] https://www.hsj.co.uk/technology-and-innovation/nhsx-all-nhs-must-have-shared-care-records-in-a-year/7028492.article

[22] Home | Goldacre Review

[23] GP Data for Planning and Research: Letter from Parliamentary Under Secretary of State for Health and Social Care to general practices in England - 19 July 2021 - NHS Digital

Figure 1.2: Uses of patient data wheel



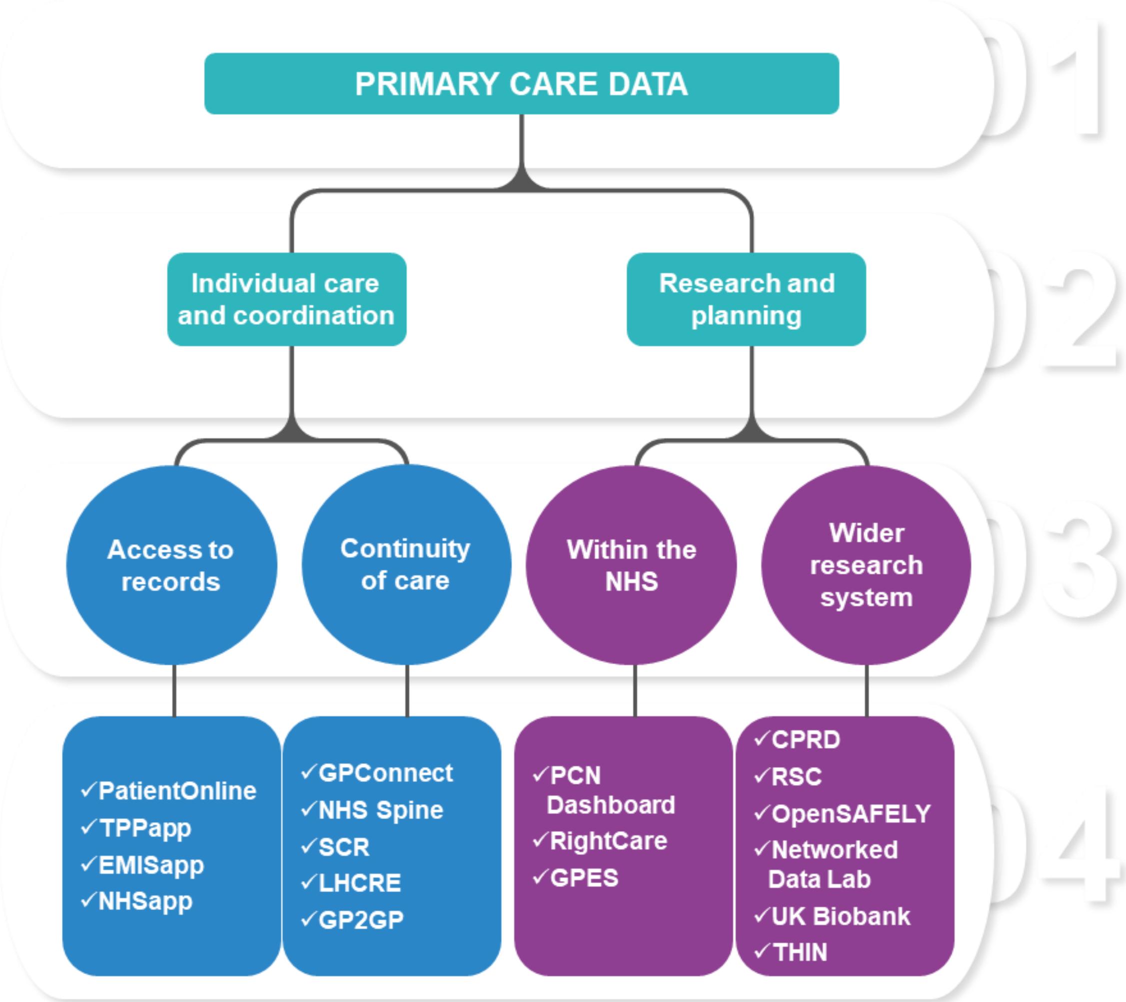
Source: Understanding Patient Data

It is widely established that data use in primary care has two key purposes:

1. Individual care and coordination
2. Research and planning.

A short schematic that outlines the different purpose for systems can be found below in Figure 2. A greater depth of information on these systems can be found in Appendix A, within the wider literature review.

Figure 1.3: Overview of common systems which enable data use in primary care



2 Aims and objectives of the study

In recognising the evolving landscape in which data is being used in primary care and across the wider health system, Understanding Patient Data (UPD), part of the Wellcome Trust, and the Royal College of General Practitioners (RCGP) set out to understand the views and attitudes of primary health care professionals on data use. This study has therefore explored:

- Primary care health professionals' views on the use of health data
- Enablers and barriers to the uptake of and advocacy for data use in individual care and coordination, planning and research
- What interventions could help to overcome the challenges expressed and engender trust in the use of health data.

In doing so, we contributed to testing the validity of the following hypothesis: *Identifying positive benefits, and minimising perceived risks, increases primary care health professionals' willingness to advocate for and support the use of high-quality health data.*

This qualitative study was undertaken with four key considerations:

- **There will be no 'one size fits all'.** Similar to the sweeping assumptions often made about 'the public', we do not anticipate there to be one common viewpoint held across 'healthcare professionals' as one unit.
- **Context is key.** From the literature review in Appendix A, it is clear that there are a number of dimensions which will influence attitudes to the use of health data. Through our qualitative engagement, we will consider the environment that individuals are working within and how this may shape their attitudes.
  - Little work in the literature has explored different voices in primary care professionals across **different communities**, in terms of how different geographies and deprivation indices consider data use. We will look to include a range of views from practices who face different challenges, enablers, and blockers.
  - In previous work, there has been little to acknowledge the baseline familiarisation with data or the **maturity of the data ecosystem**. We believe that this will likely be important in influencing attitudes to data use.
- **New roles in primary care have been unexplored.** Much of the work done to date centred on attitudes or views on health data use has focused on GPs. However, the workforce in primary care is much broader than that. We will look to explore viewpoints from a range of different roles both including, and beyond, the GP.
- **The evolving landscape could itself shape attitudes to data use.**
  - Now more than ever through the COVID-19 pandemic, the importance of data use has been given a platform and has become embedded in everyday language. Real world examples of how data is used are in the public domain and this may increase the familiarity or comfort with data use. More so, it may be one of the greatest examples of the output of using health data for research and planning.
  - The developments of PCNs in England could also influence professionals' attitudes to data use. The importance of data use for informational continuity and planning have not been explored in the past.

  These are changing times and this study will be timely in understanding viewpoints within this period of change and accelerated development of not only interventions, but thought and opinion.

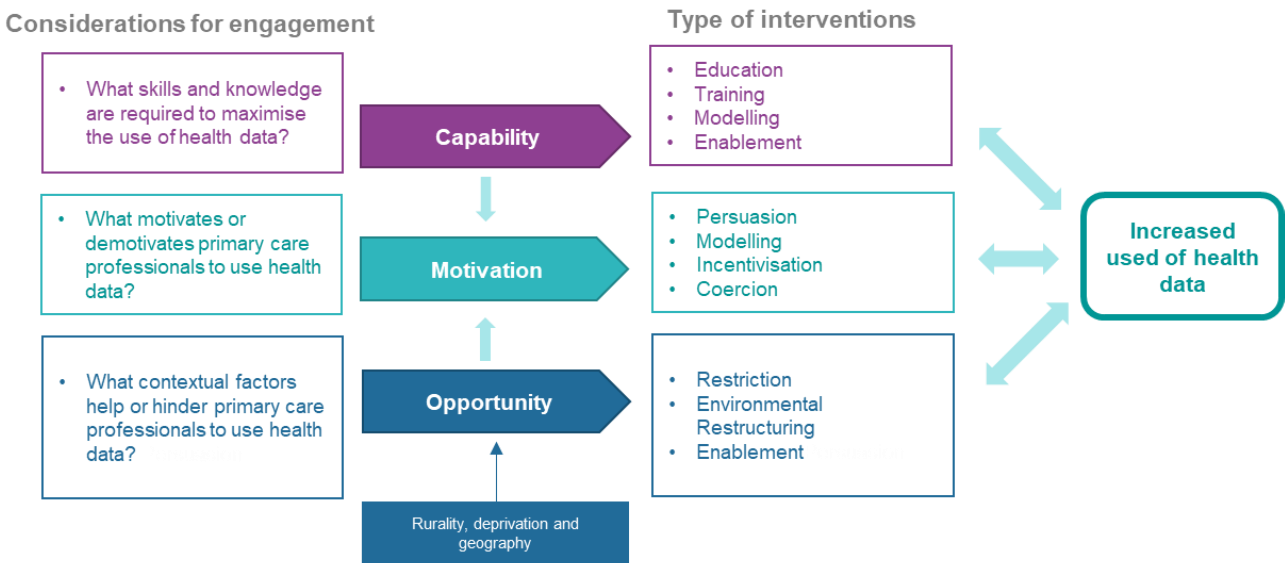
3 Methodology

The engagement phase was split into three subphases:

- Strategic stakeholder interviews
- Primary care staff interviews
- Primary care surveys to test variation and agreement of findings at scale.

The framework for this engagement is based on Michie's COM-B model[24] to unpick the capabilities, motivations and opportunities within the views on health data and areas for success through different interventions. This is outlined in Figure 3.1.

Figure 3.1: COM-B framework for professionals' attitudes to data use



3.1 Interviews

Interviews were undertaken with 37 stakeholders between April 2021 – January 2022. Stakeholders who were interviewed were nominated using the 'snowballing' approach or volunteers.

Interviews with strategic stakeholders covered a range of roles including GPs with involvement in the RCGP Health Informatics Group, the Faculty of Clinical Informatics or population health management, stakeholders involved in the development of local care record systems, NHSX, as well as wider organisations such as the Practice Managers Association, British Heart Foundation. This also covered representation across the devolved nations.

Staff interviews included a wide range of staff groups, such as partnered GPs, salaried GPs, clinical pharmacists, practice nurses, paramedics, health and wellbeing coaches, care coordinators and practice managers.

Interviews were undertaken virtually and hosted on MS Teams. Content was not transcribed but detailed notes were taken in line with the topic guide framework set out in Appendix B. Where conversations took place virtually and consent was granted, conversations were recorded for

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[24] Michie, S., M. M. v. Stralen and R. West (2011). "The behaviour change wheel: A new method for characterising and designing behaviour change interventions." Implementation Science 6(42): 11

note-taking and analytical purposes. Thematic analysis of the content was undertaken in line with set coding frames with examples described below.

3.2 Surveys

To test themes gathered from the literature review and interviews, an online survey was developed to generate scale of findings. The survey was shared directly to known stakeholders and via active forums which reach those working in primary care and included:

- RCGP members
- Primary Care Improvement Community
- Q Community – Primary Care, Special Interest Group
- RCN network
- NHS Futures for Health and Wellbeing Coaches and Care Coordinators.

The survey was open between 10th November 2021 to 26th November 2021 and received 111 responses. The number of responses for different professional roles is shown in Table 3.1 below:

Table 3.1: Roles of survey respondents

Role	Number of survey respondents	% of survey respondents
Allied Health Professional	2	1.83
Clinical Lead for the Health & Justice Information Service	1	0.92
Clinical Pharmacist	2	1.83
General Practitioner (Partner)	49	44.95
General Practitioner (Salaried or other)	48	44.04
GP Trainee	1	0.92
Practice Manager	1	0.92
Practice Nurse	1	0.92
Researcher	1	0.92
Retired GP	3	2.75

Example of survey content can be found in Appendix C.

3.3 Data analysis

Thematic analyses of the above activities were undertaken in line with the established framework[25]. Coding frames were developed with common themes to collate free-text responses, examples of these include:

- Enablers and barriers
  - *Capability*: Awareness of systems and processes; Implementation of systems and processes; Integration; Quality of data; Information Governance; Analytical capability; Capability to utilise outputs; Roles and resources to build capability

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[25] Gale, N. K., Heath, G., Cameron, E., Rashid, S., & Redwood, S. (2013). Using the framework method for the analysis of qualitative data in multi-disciplinary health research. BMC medical research methodology, 13, 117. https://doi.org/10.1186/1471-2288-13-11

  - *Motivation:* Custodian of data; Influence of patient attitudes; Understanding of purpose or use; Incentives for participation; Influence of others; Personal interest in data use
  - *Opportunity:* Time and resources; Leadership; Maturity of data ecosystem; Practice topography; The pandemic.
- Interventions or ideas for the future to address barriers
  - Education; Training; Modelling; Enablement; Persuasion; Incentivisation; Coercion; Restriction; Environmental; Restructuring.

Descriptive statistics were used for quantitative survey data to present messages.

3.4 Roundtable

On the 8th December, a virtual roundtable was held to present and validate emerging findings with an audience of six strategic stakeholders including GPs, GPs working in research, a Practice Manager and with representation from NHS Digital. This was facilitated by the RCGP Clinical Research Lead. Discussion from this group has been integrated within the findings of this report.

3.5 Limitations and considerations in the methodology

Within our methodology, we use a number of methods to answer our evaluation questions. Before any interview or survey, we must introduce the topic of data use or sharing and the aims of the study. This, of course, may result in bias responses from stakeholders on their views and motivations towards data use. However, this is not a new concept and is a common limitation facing interview-based qualitative research.

Survey methods were used to capture the scale in views from staff. We recognise that the pressures on General Practice may have limited the response rate to the survey. Insights from the RCGP RSC suggest that, for the 4 weeks prior to 19th December, appointments in General Practice were 10% higher than the same period in 2019. We are unable to attribute a response rate given the flexibility and pragmatic approach to data collection and therefore cannot provide insight to the representativeness of the sample.

The approach for recruiting primary care staff in the study was largely through volunteers and ‘snowballing’ techniques. We recognise that this can mean that the voices we have heard from are more likely to have an interest or baseline knowledge on the topic. To overcome the inherent challenge of ‘working with the willing’, we explored both new and existing networks, and with those at different stages in their career.

Over 92% of survey respondents held the role of a General Practitioner; either partner, salaried or other, trainee or retired. This should be regarded as a limitation of our survey analysis. We recognise that the responses may not be representative of the views of those in other primary care professions and cannot be generalised to all primary care professionals.

4 Primary care health professionals’ views on the use of health data

Highlights

Whilst perhaps not surprising, this study has identified that primary care professionals who responded to the survey felt most comfortable sharing data across their practice and PCN. The appetite for sharing data reduced as the data moved further away from the practice to the ICS, wider NHS and more broadly. Similar trends were seen in attitudes regardless of the purpose for which this data was being shared or used (care and coordination, planning and research) although a greater proportion of respondents were comfortable with data being shared more widely for research purposes. Qualitative comments highlighted some of the conditions which were important to this such as the appropriate anonymisation of data and information governance processes which facilitate the protection of this data.

Across professionals who work in primary care, there are varying attitudes on the use of data and how this is shared.

From initial discussions with strategic stakeholders, it became apparent that there were three core questions which underpinned these views:

- What is the purpose for which the data is being used or shared?
- Who will use the data?
- How will the data be protected?

The survey sought to probe these questions further, considering purpose and the scale at which data was being used.

For care and coordination, our activities have suggested that professionals are comfortable in sharing data within the practice and across the PCN, but the appetite for this reduces when sharing with wider NHS bodies and third parties. From our survey, 94% of primary care health professionals agreed[26] that they were comfortable sharing data for patient care and care coordination across the practice (n=105) but this decreased to 17% of respondents who agreed they were comfortable sharing more widely beyond the NHS (i.e. to a trusted source or third party organisation) (n=18). Primary care health professionals felt less comfortable in sharing data for patient care and care coordination the more widely the data would be shared, as shown in Figure 4.1. Nonetheless, through our interviews with professionals, examples were given as to where there could be benefits from improved data sharing with other parts of the system, including district nursing and social care teams for example. These benefits spanned both patient outcomes as well as improved efficiency for the primary care workforce.

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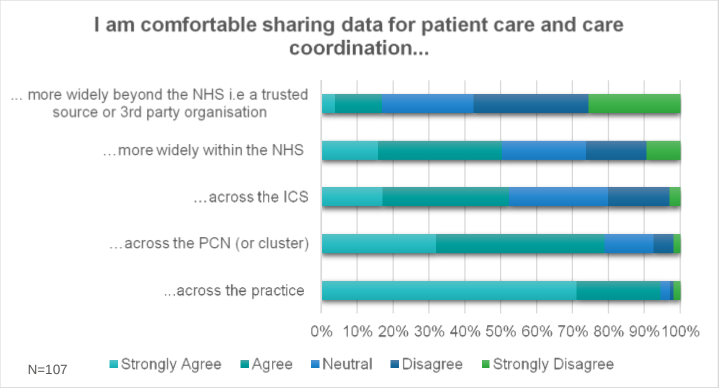
[26] Agreed or strongly agreed

Figure 4.1: Survey results: Sharing data for care and care coordination



Our engagement highlighted that there was enhanced importance of data sharing for particular patients or cohorts of patients, for example, those with complex needs who require care and support from different providers, including across the local authority; *“In one of the services that I was a clinical lead, we had patients who were homeless or had come out of prison, for example, and actually having data sharing was really useful”*. A prominent example was drawn from the experience of a Care Coordinator who specialised in supporting patients with learning disabilities and mental health needs, and there was a need to ensure capacity for consent with the patient or seeking consent from the carer, who could be hesitant.

Respondents were also asked to assess how comfortable they felt in sharing data for planning and responses were very similar to that of care and coordination; as shown in Figure 4.2.

Figure 4.2: Survey results: Sharing data for planning

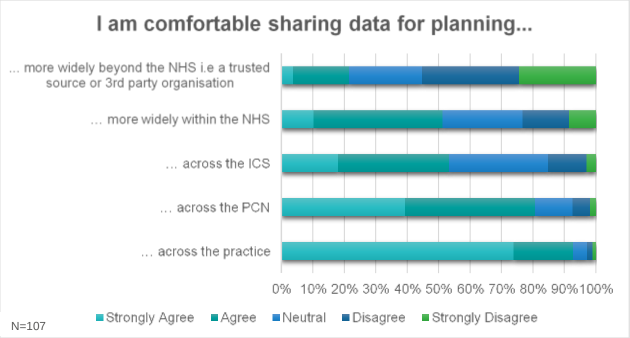
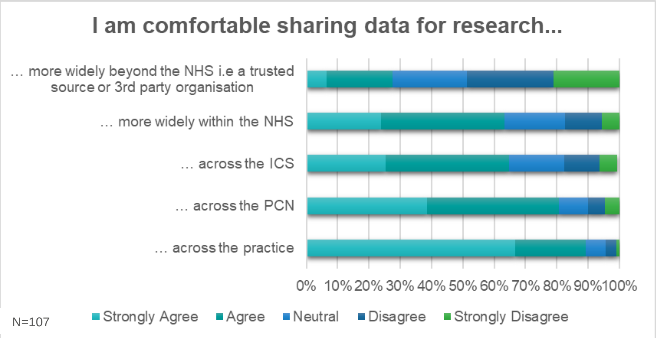


Figure 4.3: Survey results: Sharing data for research



For research purposes, as shown in Figure 4.3, there is a similar trend where primary care professionals naturally feel more comfortable in data use and sharing closer to practice and PCN. 90% of respondents agreed they were comfortable sharing across the practice (n=99), but only 27% agreed they were comfortable sharing more widely beyond the NHS (n=30).

Whilst this was similar to the responses to sharing data for care and coordination, a higher percentage of respondents agreed that they are comfortable in sharing data for research purposes across:

- The PCN (81% for research purposes compared to 79% for care and coordination)
- The ICS (66% for research purposes compared to 53% for care and coordination)
- More widely within the NHS (65% for research purposes compared to 51% for care and coordination)

- More widely beyond the NHS (28% for research purposes compared to 18% for care and coordination). Interestingly, there was less resistance for data sharing with third party academics or pharmaceutical research than was first hypothesised.

Examples of the comments which accompanied these responses:

- *“Shared communication improves safety and quality of patient care. Most patients do not know all the details of their care particularly details from the past, they don’t realise they may be relevant”*
- *“So long as it is handled correctly, data can provide a huge wealth of information, of great value to current and future patients”*
- *“I think it is helpful for children's services to access child records when there are safeguarding concerns”*
- *“I believe that patients data should only be shared when absolutely necessary and with their express permission”.*

Qualitative comments also highlighted the conditions of data use which underpin this attitude with common themes of:

- The purpose for which it is being used, including to advance quality of care or treatment

  “Depends on the planning need, but if it can be assumed that data will be used to improve public health or to facilitate rational use of NHS resources then I don't see a problem”
- The users and beneficiaries of data use

  “As long as personal data is secure, the statistical data should be used widely, except … for outside NHS, unless they are government sanctioned or work officially for government or NHS”
- Ensuring data is appropriately safeguarded, anonymised if appropriate and that data sharing protocols and agreements are in place

  “Important to this is the appropriate anonymisation of data and information governance processes which would facilitate the protection of this data”
- Ensuring appropriate consent is in place.

  “As long as the patient is happy and consents to this I see it as a positive step in providing the best care for patients. My feeling is that patients would be surprised to hear that this maybe doesn't happen”.

When considering the representativeness of these findings, it should be noted that 72% of survey respondents indicated that they also have a professional interest in the use of data and so may have a greater appetite for data use, as well as a better understanding of the conditions described above which enable the safe sharing of data for research purposes. Section 5.2.6 discusses the impact of personal interest further.

The small number of respondents in wider clinical roles and from devolved nations means that it is not possible to draw meaningful conclusions about where there may be variation to the findings described above.

5 Factors which influenced attitudes to data use

Highlights

There are a range of factors which influence the attitudes of primary care professionals to use and share data, affecting their capability, motivation and opportunity to do so. Each of these factors is important in their own right but they do not exist in isolation, and it is their combined influence which is ultimately shaping behaviours around data use.

Across the spectrum of primary care health professionals engaged with as part of this study, it is apparent that there is a strong sense of responsibility for safeguarding of patient data, alongside a view that data use for care and care coordination, planning and research is needed to provide the best quality patient care possible.

For GPs, and particularly those GPs who may be partners, the contractual and legal responsibilities of information governance and data protection were most commonly mentioned, alongside the professional responsibilities as a custodian of patient data. Whilst our survey results suggest that nearly all professionals understand these requirements, processes and responsibilities, these GP stakeholders have described to us the challenges in navigating these, accessing support where this is needed and the fear that this can generate. From qualitative engagement in this study, a picture was painted where GP partners sit at the nucleus of the practice as the data controller. The further away that primary care professionals sit from the practice, the less anxiety is felt towards data sharing.

Whilst professionals have a strong sense of responsibility for safeguarding of patient data, at times through our engagement, there has been a sense that data use or research is distinct from a primary care professional’s core role. Whilst some GPs have described a reliance on their administration teams for good coding, others have described the importance of every professional having a responsibility for data quality and record curation.

Time and resources are clearly a limiting factor within General Practice, but practice culture is also important in shaping attitudes and behaviours. Clinical leadership supported by practice management and an effective administration team enables professionals to feel empowered to use, interrogate and share data, participate in research and improvement studies and to confidently talk to their patients about how their data is used and safeguarded. It was also considered that a practice’s own data eco-system and the extent to which they had been involved in data driven projects has some influence. Professionals reflected that where practices have been on a journey to build understanding of how data is extracted, anonymised and used safely and for what benefit, trust is built and they are more likely to become involved in data driven projects in the future.

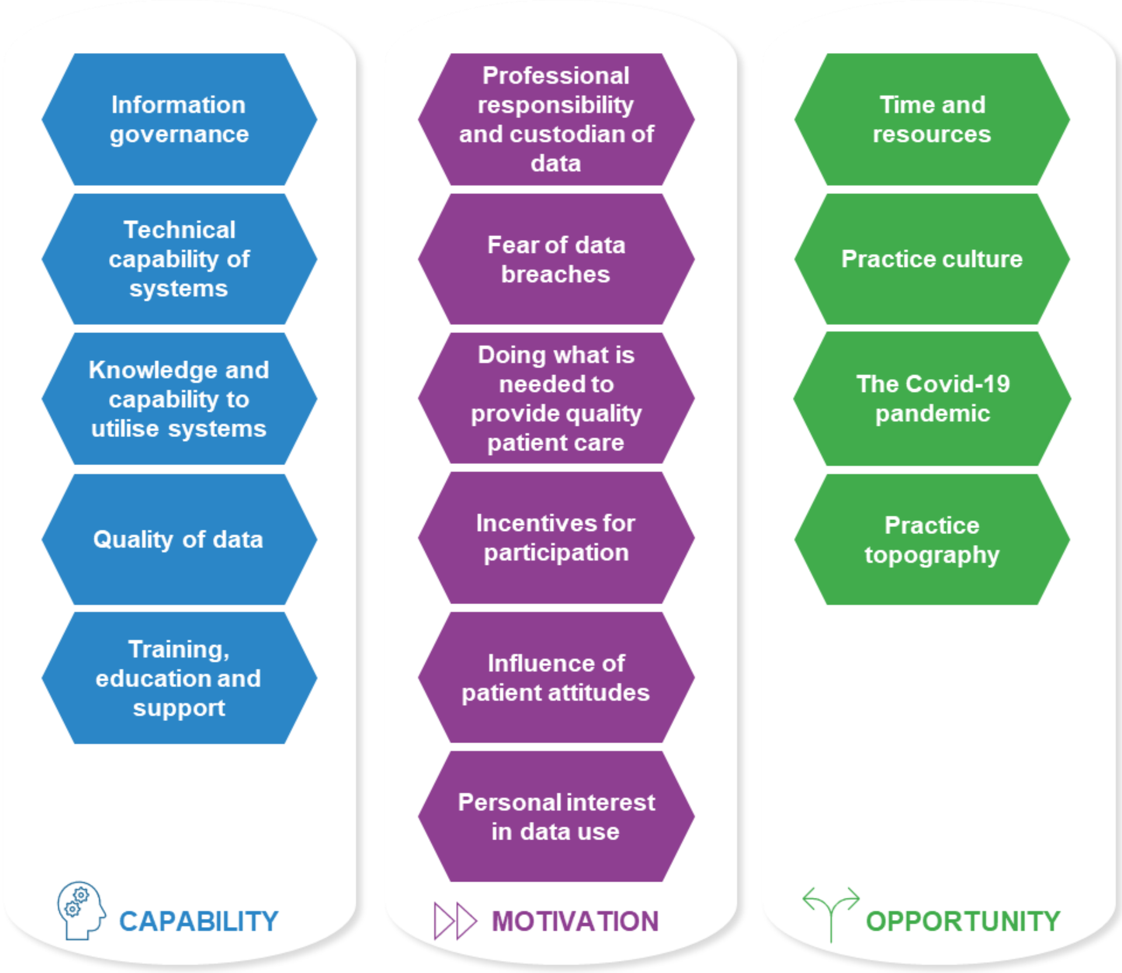
Whilst data protection officers were mentioned by some stakeholders as a source of support, their visibility and the level of support they provide is reported to be variable.

The influence that primary care professionals and patients have on each other’s attitudes to data sharing is an interesting finding. Whilst there is a spectrum of views from patients about how their data is used, patients were described to rarely question data sharing with primary care professionals. Stakeholders did describe the unconscious influence that primary care professionals may have on patients, for example in sharing opt out forms as part of usual practice and without explanation.

This section of the report outlines contributing factors which have influenced the attitudes to data use as described in Section 4. More specifically, it addresses a key objective of the study, to “explore the enablers and barriers to the uptake and advocacy for data use in individual care and coordination, planning and research”.

Figure 5.1 below provides an overview of the factors identified and aligns them to the COM-B framework to help us understand behaviour.

Figure 5.1: Factors influencing attitudes to data use



Within this section we describe each COM-B condition of capability, opportunity and motivation in turn, discussing the contributing factors within each. Each factor is a continuum, acting as an enabler or barrier depending on where each individual sits on that spectrum.

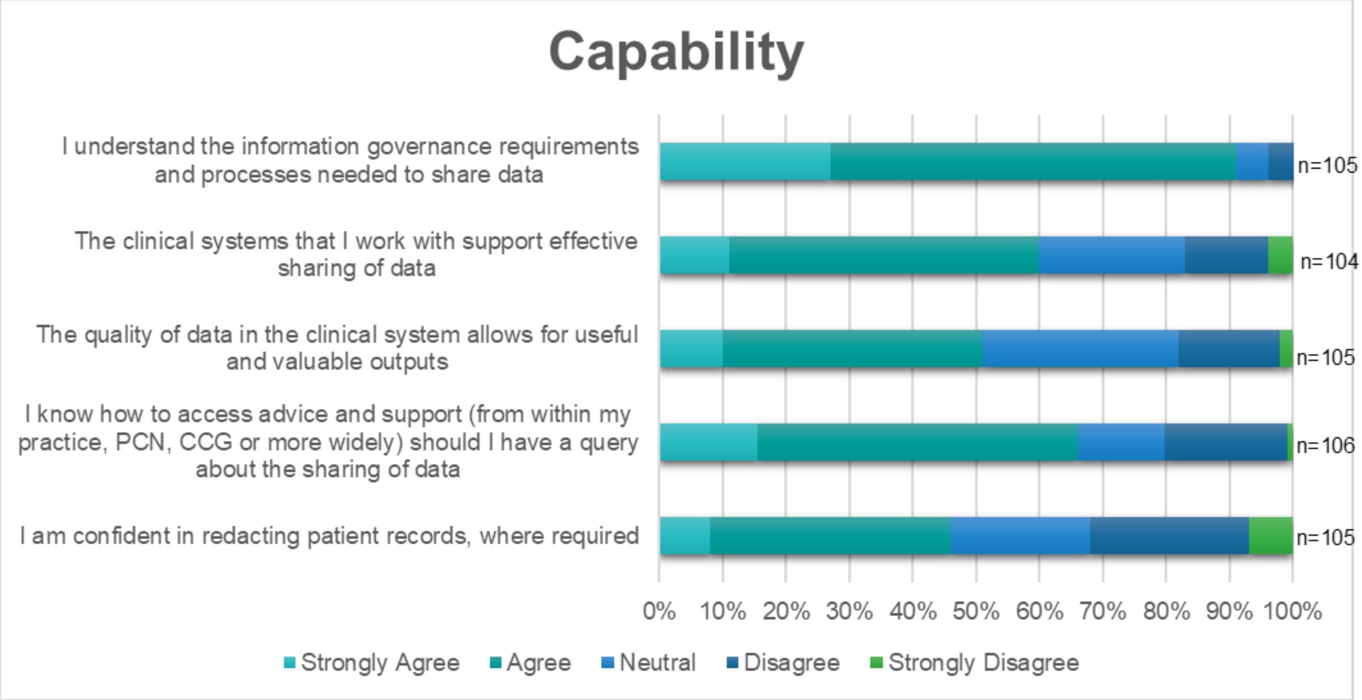
It is also important to highlight the dynamic nature of these conditions, something which is reflected on at the end of this section.

5.1 Capability

- Stakeholders, and particularly GPs and practice managers, most commonly described **information governance and data protection duties** as being important in shaping behaviours around data use. Whilst nearly all survey respondents agreed that they understand their professional responsibilities for the safeguarding of data, one in five did not know how to **access advice and support** should they have a query about the sharing of data.
- The **technical capability of systems** to facilitate the safe sharing of data for patient care was also commonly described by all primary care professionals. All primary care professionals described having the capability to utilise their own practice systems for the purpose of direct care. Beyond the practice however, opportunities for improvement were highlighted, including the sharing of information with wider health and social care services, and increasing knowledge of big data initiatives or research databases.
- For many, therefore, whilst **data quality** is a challenge, it was felt that this should not be a deterrent to data use.
- Over a third of survey respondents disagreed or strongly disagreed that they were confident in **redacting patient records**.

Figure 5.2 provides an overview of survey responses to factors associated with capability. Each are then discussed below.

Figure 5.2: Survey results: Factors relating to capability



5.1.1 Capability: Information governance

The contractual and legal obligations of a practice with regards to information governance and data protection were commonly described by GPs who were partners within a practice or, who had more years of experience in working within General Practice. This was also described by practice managers. Concerns around breaching compliance with these obligations were commonly mentioned as a barrier to the sharing data and this is explored further in section 5.2.1

below. As part of their decision making, it was therefore felt that GPs need to be assured that the benefits of sharing data outweigh the risks of sharing this.

Interestingly, whilst this emerged as a key theme from our qualitative interviews, from our survey, 89% of primary care professionals agreed that they understood the information governance requirements and processes needed to share data (n=97) and of this, 25.7% stating that they strongly agreed (n=28). Only 5.5% disagreed with this (n=6), with no professionals strongly disagreeing. 95.4% of respondents also agreed that they understand their professional responsibilities for the safeguarding of data, (n=104), with 51.4% of respondents stating that they strongly agreed (n=56).

Combining these insights, this suggests that professionals have an understanding of the information governance requirements and processes by which they must operate, yet these are still considered to be an important factor in influencing their attitudes to data use.

To enable the sharing of data in this context, many GP and practice manager respondents highlighted the importance of having clarity about information governance processes. Some reported it to be challenging to navigate these processes, with GPs highlighting for example that "the environment is so complicated" and that "the constant updates to guidance are a barrier" which can make it difficult to maintain knowledge. These frequent updates are felt to compound this ability to navigate and adhere to appropriate information governance processes, which can in turn contribute to a sense of "fear" which is explored further in 5.2.2.

From a research perspective, respondents described a belief that information governance processes can currently also act as a barrier to research requests, also noting how updates to guidance can mean that practices withdraw from research studies when consent forms require updates.

5.1.1.1 Guidance and support

From our survey, 66% of primary care professionals agreed that they knew how to access advice and support (from within their practice, PCN, CCG or more widely) should they have a query about the sharing of data (n=72). In contrast, 20.9% disagreed or strongly disagreed (n=23).

Respondents reported seeking information governance advice about these legal obligations from a range of sources from both within the practice and the wider system. This included partner GPs, GPs with particular interest in data, their practice manager, as well as more widely the Caldicott Guardian, Data Protection Officer (often within their local Clinical Commissioning Group (CCG) or Local Medical Council (LMC). For some, being able to access this support was felt to be a challenge; "we don't have right people, who know enough".

The role of the Data Protection Officer provided some interesting discussion. Through interviews, some GPs were uncertain as to who their local Data Protection Officer might be, whilst others described a much closer working relationship. Similarly, some described their local Data Protection Officer as an important source of information and support, whereas others described how they could actually become an additional barrier to data use. In one example, a GP described how the Data Protection Officer had built fear across the local practice management teams, alongside sharing onerous data impact assessment guidance.

For those who access support through their LMC, it was felt that the advice they might receive could vary depending on the attitudes of LMC members, with some felt to be more progressive and supportive of data use for 'secondary uses', compared to others who may be more risk adverse.

Stakeholders reported how a data protection lead in each practice would be important in building trust and ensuring that information governance duties are adhered to.

For practices participating in the RCGP Research and Surveillance Centre (RSC), the team have found that practices welcomed the DPIA template that has been developed, allowing practices to adapt this for their local context. Materials have also been developed to promote local understanding of how data is extracted, anonymised and held securely.

5.1.2 Capability: Technical capability of systems to facilitate the integration of information across providers

From our survey, 59% of primary care professionals agreed that the clinical systems they work with support effective sharing of data (n=63). 16.8% disagreed with this statement (n=18) and 3.7% strongly disagreed (n=4).

Respondents have described to us the frustrations in not having a unified Electronic Health Record. Within primary care, different systems are not interoperable and "don't talk to each other", although it recognised that there have been attempts to address this. GPs, pharmacists and paramedics working in primary care have described the frustration of being unable to write to a patients record when they are working from an out of hours service, home visiting service or a community pharmacy. This contrasts with having full access when they are practice based. One professional commented how this constrained access makes it challenging to make an informed decision and does not utilise their skills appropriately; they "can be more than eyes and ears as an autonomous prescribing professional". With the development of new roles in primary care, it is also apparent that not all have access to the patient's full record. One respondent described how the wellbeing practitioner in the practice does not have full access to their records.

Primary care professionals have also described challenges in the technical capability of systems to allow effective data sharing across the patient pathway:

- There have been mixed views with regards to **data sharing with secondary care** with some suggesting that systems allow data to flow "in line with expectations" and "fairly quickly". Others have described how this can be inconsistent, with a frustration that GPs can only access basic, limited information from local hospital providers. A practice manager described how this can result in inefficiencies. For example, it takes time to access password protected emails coming into the practice, sometimes to discover that the patient in question is not registered to their practice and requires directing on to another practice. A GP also highlighted the limitations of secondary care clinicians being unable to access the primary care records and the safety implications for patients with addiction and abuse of prescribed medications, for example.
- Whilst there have been some local examples as to where primary care information is shared effectively with wider community services, such as a district nursing service, there is an appetite to improve the sharing of data across health and social care services. This includes **care homes, health visiting, school nursing and social care teams.** GPs, care coordinator and pharmacist respondents described the **safeguarding and efficiency benefits** associated with this.
- In secure environments, advances have been made in the safe transfer of patient information through Offender Health IT, in connecting this to NHS Spine and through the (soon to be implemented) GP2GP, which will allow a patient's full record to be transferred to the secure setting with their consent. Within the secure environment, data is used and shared effectively with wider services, including mental health and substance misuse teams. However, there is a recognition that systems constrain the sharing of information with the community based mental health and substance misuse teams, when an offender is released.

It was also highlighted that a unified system would enable research to happen at a greater scale.

5.1.3 Capability: The knowledge and capability of professionals in utilising systems and processes which enable data use and sharing

All primary care professionals described having the capability to utilise their own practice systems for the purpose of direct care. They also described how themselves or members of their wider practice team (practice managers and senior administrators) were able to utilise the systems to support practice audit, planning, research or quality improvement. This includes the ability to run system queries or be able to utilise reports extracted from their systems.

Many of the GPs we spoke with said that they would direct patient queries regarding data protection to practice management, although 68.5% of primary care professionals also agreed or strongly agreed that they feel confident in talking to patients about how their data is safeguarded (n=74). In contrast, 19.4% of professionals disagreed or strongly disagreed with this (n=21).

With regards to data being used and shared beyond the practice, there were several gaps in knowledge or capability which were highlighted:

- Whilst the frustration in the technical capability of systems has been described in section 5.1.2, a common theme highlighted by respondents has been a lack of understanding of the pathways in which data is shared or used. "I think if we knew the pathways were clear, we knew where we were sharing that information, I don't think they have a problem with it".
- Several salaried GPs reflected that they had the awareness and capability of the systems required to do their role; but were aware to a lesser extent of data sharing, big data initiatives or internal NHS systems such as RightCare.
- For research purposes, a number of GPs described the confusion in navigating the different registries and databases, alongside understanding the information governance implications associated with each. Indeed, some GPs (who tended to be salaried), were not familiar with central research databases, such as RSC or CPRD, although they believed that others in the practice such as the practice manager or lead GP would probably be aware of this.
- A few respondents also described how some systems, developed for the purposes of research and planning, are "so secure it is unusable and actually provides a barrier to research and planning".

In overcoming this barrier, some respondents reported that where practices have been involved in population health management, retrospective studies or Q research for example, they have been able to build understanding of how data is extracted, anonymised and used. As a result of being guided through this process, for future programmes, practices are reported to be "better equipped to know which questions to ask and of who; making their involvement more likely".

In parallel, a small number of GPs described their own lack of awareness or understanding about the levels of information that patients can access, for example describing a lack of understanding as to why some patients can see more of their records than others.

It was also highlighted that for patients to gain access to their detailed coded record via the NHS App, patients are required to request this from their practice. This was felt to be a barrier as some practices are not aware of the role that they have in enabling this, and given that the process is not digitised, some patients are reported to "get a mixed response" to this request.

5.1.4 Capability: Quality of data

5.1.4.1 The quality of data as a deterrent to data use

From our survey, 50% of primary care health professionals agreed or strongly agreed that the quality of data in the clinical system allows for useful and valuable outputs (n=54), in contrast to 20.1% of respondents who disagreed or strongly disagreed (n=22).

Many of those we engaged with reflected that the quality of data can often be a barrier to data use, both for clinical practice as well as for the purposes of research and planning. For example, respondents highlighted:

- Poor coding practices or missing information, some of which has been identified as part of the pandemic response to identifying clinically extremely vulnerable patients
- Inconsistencies in coding, for example how different professionals such as paramedics are recorded within the clinical record
- The challenge in receiving the clinical records from new patient registrations via GP2GP which may have missing or incorrectly coded information
- The difficulty in removing incorrect information from a patient's record which may have been recorded by a different professional or provider
- The challenge that some professionals may feel in being able to collect certain information which may be "on the margins of healthcare", for example with regards to learning disabilities or being a carer for example.

Nonetheless, many described to us how the quality of data has improved over time, with the implementation of the Quality Outcomes Framework[27] having an important role in improving coding, albeit on the specific areas to which QOF is focused. It is recognised that some consider QOF to be too limiting and in Scotland the scheme was retired in 2016. Other GPs described how Population Health Management presents an opportunity to build on this further; describing how primary care has *"made progress [with regards to data quality] but progress to come".*

For many, therefore, whilst data quality was considered to be a challenge, it was felt that this should not be a deterrent to data use, with one GP summarising *"don't let perfect be the enemy of the good".*

5.1.4.2 Personal responsibility for data quality

For meaningful data to be available for sharing, some GPs reflected that there is an *"onus on the GP"* to keep, maintain and curate a patients' record. This is something that takes time but is important to both patient outcomes and the efficiency of primary care. A practice nurse reflected that this actually becomes a barrier to other roles writing to the patient record; "*I know that there are a lot of the concerns of people putting information into the GP records, so adding in diagnosis or adding in treatment plans. In general practice, they like be in control of …what is in the patient record*".

As part of this record curation, one GP highlighted how it is not always clear what is relevant to share with other agencies as part of this; for example, whilst it is relevant to share information about a diabetes condition, an attempted suicide two decades ago may not be appropriate to share for many other system partners.

The individual responsibility of different primary care professionals and the inputs they make to the patient's record may be perceived differently depending on your role, your employer (a practice or perhaps a PCN) and your interest in data use. For example, one GP described a perceived cultural change in General Practice with salaried GPs and other additional roles having less of a direct interest in the quality of the records as they *"don't have a stake in the efficiency of the practice".* The GP also described how if a record is not maintained properly, this can encourage others to simply add to this, rather than review the record in its entirety, whilst potentially impacting on outcome and efficiency. Instead, "*everybody entering data into the system, needs to have a stake in it*" and this should be part of their basic training.

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[27] QOF aims improve the quality of care by rewarding practices for the quality of care they provide to their patients, based on a number of indicators across a range of key areas of clinical care and public health

Other GPs have described how having an effective administrative team with coding expertise allows for greater efficiency enabling them to focus on their clinical role.

5.1.5 Capability: Training, education or accessing additional support

Through our engagement, GPs highlighted the limited access to analytical capability in primary care and the impact this can have on constraining involvement in planning and research activities. Involvement in quality improvement initiatives was felt to have made some progress in enhancing analytical skills in practices and encouraging the best use of systems, but this was not considered to be sufficient. Some described how informal relationships had instead been formed with CCG analysts or system providers to help navigate some of these issues. One GP reflected how the educational drive which supported the transition to electronic GP records was very strong. However, over the last decade, aside from good practice guidelines, there has been little education on data quality, with no or little formal training on how best to capture and use data for example. Both GPs and Practice Nurses described how education programmes should cover the importance of data quality, coding and record curation.

With regards to training around information governance and data protection, GPs and practice managers both highlighted that additional training would be beneficial. All professionals described the range of training or education materials that they could access, including for example mandatory e-learning modules, local practice or PCN protected learning sessions or access to toolkits such as those on the RCGP website. There is a recognition, however, that due to the capacity and time pressures that many GPs experience, some GPs are likely to prioritise clinical updates or the areas which are of personal interest to them, rather than additional training on data use. It was also felt that those in leadership roles in this area, such as Chief Information Officers and Data Protection Officers do not have the resources to be able to reach out and support this education.

5.1.6 Capability: Redaction

As part of the GMS contract requirements to offer online patient access to full patient records, the issue of redacting sensitive free text information has become apparent over 2021. From our survey, 45% of respondents agreed or strongly agreed that they were confident in redacting patient records (n=48). 38.3% of survey respondents disagreed or strongly disagreed with this statement (n=41).

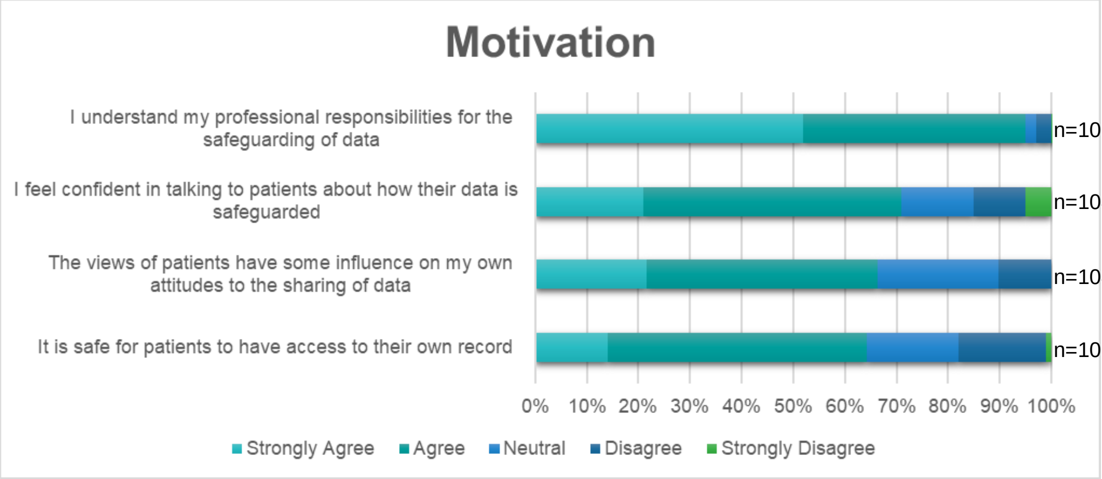
Whilst the ability to hide a record from patient view is in place for most practices as a safeguarding measure and national guidance has been developed, some GPs spoke of their concern about the time taken to ensure historical records are appropriate for sharing. They particularly highlighted the safeguarding risks associated with domestic violence for example. There was also a recognition that this requirement may mean that GPs will change how they record free text comments from the consultation to ensure that these will be interpreted appropriately by the patient. Where there are safeguarding concerns, on an exception basis, two patient records may need to be created and maintained.

5.2 Motivation

- Across the spectrum of primary care health professionals, it is apparent that there is a strong **sense of responsibility for safeguarding of patient data**, alongside a view that data sharing is needed to provide the **best quality patient care** possible.
- There is a recognition, however, that **without developed capabilities**, this responsibility as a custodian of data can become a demotivating factor for data sharing. This is often born from **fear of breaching** these responsibilities, compounded further by historical examples of data breaches.
- The **views of patients and primary care professionals** on data use both influence each other. Professionals report a range of views from patients and often misconceptions about how their data is already handled and shared.
- Those primary care professionals with an interest in data feel more comfortable in sharing data for research purposes. For some, data use and research appeared to be considered as **distinct from a primary care professional's core role**.

Figure 5.3 provides an overview of survey responses to factors associated with motivation. Each are then discussed below.

Figure 5.3: Survey results: Factors relating to motivation



5.2.1 Motivation: Professional responsibility and custodian of data

From our survey, 95% of primary care professionals agreed that they understood their professional responsibilities for safeguarding of data (n=104), with 51% stating that they strongly agreed (n=56) and 44% agreeing (n=48). Only 2.8% of survey respondents said they disagreed with this statement (n=3), all of which were GPs.

GPs (and particularly GP partners) are 'data controllers' or the 'custodian of data' for their patients' data and even if they use a third party to process the data for a specific purpose, they remain the data controllers and responsible for the safe handling of the data. Whilst the responsibility is typically GP held, practice managers in larger practices may hold some of this responsibility. The data controller role has been described to influence the motivation or demotivation for data sharing.

Interestingly from within our survey, of those who agreed that they understood their professional responsibilities for safeguarding of data, 44% were partner GPs (n=48) and 44% were salaried or other GPs (n=48), suggesting that salaried GPs understand and experience these responsibilities just as do GPs who are partners. The remaining respondents who agreed with this statement included a GP trainee, Clinical Lead, as well as those in wider primary care roles which included allied health professionals, clinical pharmacists, practice nurses and a practice manager.

It is fair to say that across the spectrum of primary care health professionals, there was a sense of responsibility, however they generally have less fear than described by partner GPs.

5.2.2 Motivation: Fear of data breaches

Whilst this study paints a positive picture that there is a strong sense of personal responsibility, without developed capabilities, this can become a demotivating factor for data sharing and often born from fear.

GP partners as independent contractors hold personal liability for data breaches and, through our engagement process, there was a recognised anxiety surrounding this. Should breaches occur, this would incur fines, could lead to bankruptcy and potentially termination of their registration with the General Medical Council (GMC). Historical examples of data breaches go on to influence views and create barriers to data sharing.

Much of the fear was described to stem from a lack of control in terms of leakage, an anxiety to where shared data may end up. This was compounded by what at times was felt to be, "*excessive regulation*" and therefore a fear of the impact that this may have. One salaried GP described, *"there is a balance between risks to confidentiality and risks of making data inaccessible when it is needed. Needs to be culture where these issues are discussed and not too punitive where honest mistakes are made".* It could be perceived that some professionals felt that it was a safer option to not be part of data sharing initiatives and activities. This sense of fear was also reflected by practice managers, describing "a sense that they are "*damned if they do and damned if they don't [share]*".

A small number of respondents described how DPOs had a role in heightening this fear, rather than supporting practices to manage this.

5.2.3 Motivation: Doing what is needed to provide quality patient care

A common theme from many working across primary care was that data sharing is needed to provide the best quality patient care possible. This example was used both in terms of care and care coordination and for research and planning for future treatment and services.

This was strengthened when the data was not identifiable; *"Well, if you're doing it for patient benefit, then I don't see what problem is. As long as it's not identifiable."*

Some stakeholders highlighted specific opportunities where further research could be undertaken with this aspiration. For example, it was recognised that there could be significant learning on issues such as prevalence of certain conditions and the influence of health inequalities if data from secure environments could be shared securely with research databases such as RSC.

5.2.4 Motivation: Incentives for participation

A key motivator to get involved with data sharing initiatives was the useful outputs which can go on to shape patient care, local planning and research. One GP commented that in order to get *"GP's and their teams on board in the first instance providing data which they see as useful to them and their patients for the current coordination is one of the first key steps...once you do that, you're more likely to gain the trust".*

However, timescales to realise the benefits of secondary uses can often be longer than desired, for example the benefits associated with research and population health management, for example, may take longer to be realised, although there are examples of the latter which are more immediate.

There were some anxieties and barriers described of how data can be used for performance management. At times, that could be a demotivating factor to become involved in wider data sharing initiatives. However, there was a recognition that data sharing can go to add to the practices' own evidence base to support CQC inspections, and awards such as the RCGP Quality Practice Award. It was also described that compared to secondary care, primary care is less developed in recording activity. As we emerge from the pandemic and public pressures are placing a spotlight on primary care, *"practices want to demonstrate how busy they are and what they have been doing".* That was believed to be a factor in getting more involved and motivated to share data to evidence the activity and pressures being faced.

In the past, financial incentives have shown to be successful to improve data use and sharing. The key example can be demonstrated through the widespread uptake of the Quality Outcomes Framework (QOF). Other examples include

- Opportunities for practices to participate in funded studies via Clinical Research Network (CRN), part of NIHR and commissioned by DHSC
- RSC monitoring information can be used to provide evidence of number of vaccinations which can be used to claim payment from CCGs.

Practically, there was a suggestion that practices with established business managers may be more involved in funded research given the financial incentive for involvement.

5.2.5 Motivation: Influence of patient attitudes on data use and sharing

From our survey, 66% of primary care professionals agreed that the views of patients influence how they feel about data sharing (n=71). However, there are a spectrum of views from patients and often misconceptions, about how their data is handled and shared.

From those engaged as part of this study, patients were described to rarely question data sharing with primary care professionals. One GP did outline a recent example where patients were spurred to opt-out of data sharing after awareness of the upcoming GPDPR activation.

A frequent comment was that patients were often surprised at how little integration there is of their data across the health care system. They often assumed that their records and information are available right across their care spectrum. Interestingly, this was a point of frustration for some professionals as part of this study (see section 5.1.2).

Specifically related to patients having full access to their records, there was some anxiety shared, generally by GPs. This nervousness often centred on patients having visibility to what the clinician had written in their notes and how this may be interpreted or perceived by patients with little or no context. One GP described how they had received a formal complaint from a patient due to the content in the patient's notes; this prompted a reflection that patients can be focused on detail of individual entries, whereas for the GP the record is used to look at the bigger picture.

An emerging theme in the latter stages of engagement in this study raised queries over the safety of patients having access to their own records, alongside the issue of redaction which is discussed in section 5.1.6. From our survey, 64% of primary care professionals agreed or strongly agreed that it is safe for patients to have access to their own record (n=68). In contrast, 17.9% of survey respondents disagreed with this statement (n=19).

An interesting comment from a practice nurse suggested that clinicians may impart their anxiety on patients regarding data sharing: *"I don't know if we put the anxiety on patients about data sharing… sometimes I feel that, I have no evidence to support it, but that we create that anxiety in our patients. And actually, what we need to do is the opposite. Assume that they know that we're going to treat their data with care and not share it with everybody".* Whilst this was not reinforced by other stakeholders, it does present a fascinating perspective.

5.2.6 Motivation: Personal or professional interest in the use of data

72% of those surveyed described that they have a professional or personal interest in data (n=80). 42% of those who expressed a professional or personal interest in data were GP partners (n=33), 47% were ‘salaried or other’ GPs (n=37) and other roles included practice managers, practice nurse and clinical pharmacist.

From our survey, of those respondents who described themselves as having a personal or professional interest in the use of data, 18% agreed they are comfortable in sharing data for research purposes more widely beyond the NHS i.e., a trusted source or third party organisation (n=20). In contrast, of those respondents who described themselves as not having a personal or professional interest in the use of data, 7.2% agreed they are comfortable in sharing data for research purposes more widely beyond the NHS i.e., a trusted source or third party organisation (n=8). This suggests that primary care professionals with a professional interest in data feel more comfortable in sharing data more widely for research purposes.

Some professionals included in this study described the fact that data use is contributing more widely to patient outcomes as a motivating factor, providing this is shared securely (for example, vaccine effectiveness datasets for Public Health England or yellow card adverse events monitoring). At times there was a sense that data use or research is distinct from a primary care professional’s core role: *“It’s not my problem as we are barely keeping on top of workload”.*

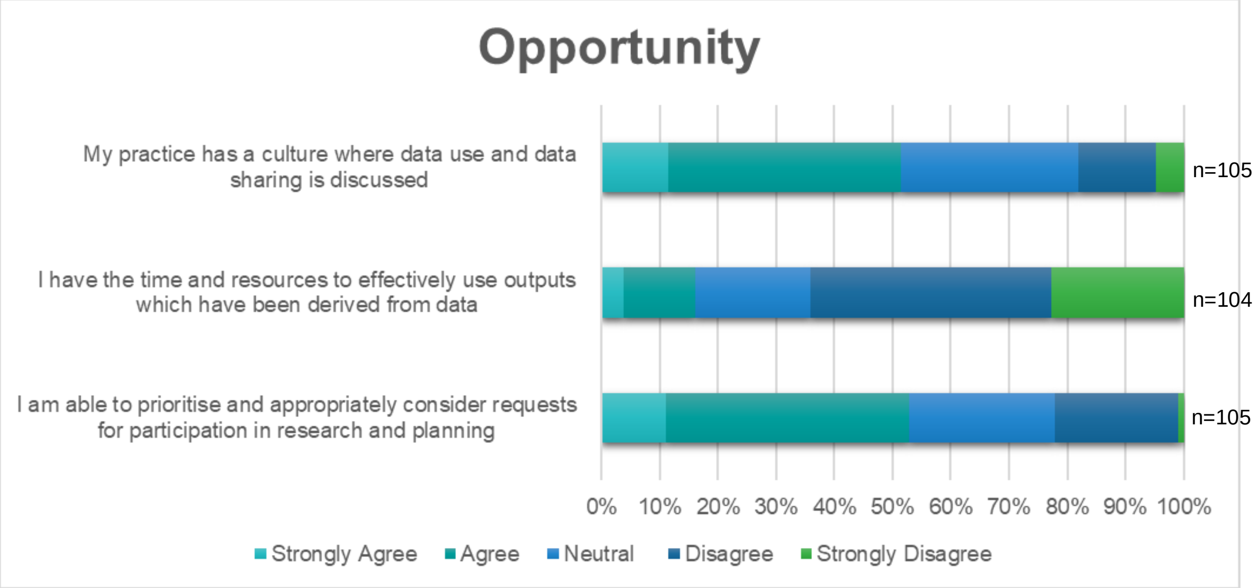
In terms of those driving involvement in research, it is not just GPs. For example, we have also heard accounts from nurses, practice managers, business managers, paramedics and research staff who have an interest and can then influence their GP partners to become involved in initiatives.

5.3 Opportunity

- **Time and resources** in primary care are clearly a constraint to data use. Less than one in five survey respondents reported that they had the time and resources to effectively use the outputs that have been derived from data.
- **Practice culture** is important in shaping attitudes and behaviours. **Clinical leadership** and effective **practice management** enable professionals to feel empowered to use data and participate in research and improvement studies.
- A practice's own **data eco-system** and **previous involvement** in data driven projects also shapes views, building understanding and trust.
- The COVID-19 pandemic has highlighted the importance of data use and clinical research, with **increased participation** in data sharing initiatives such as the RCGP RSC.

Figure 5.4 provides an overview of survey responses to factors associated with opportunity. Each are discussed below.

Figure 5.4: Survey results: Factors relating to opportunity



5.3.1 Opportunity: Time and resources

From our survey, only 16% of primary care professionals agreed that they had the time and resources to effectively use the outputs that have been derived from data (n=17), whilst 64.2% disagreed (n=68). 22.6% of survey respondents strongly disagreed (n=24).

It was described that the *"pressure on General Practice is sky high"* with the clinical workload, supporting the vaccination programme and increasing burnout. Some described that they do not have the capacity or headspace to participate in data initiatives nor utilise the outputs that would come from participating. One GP partner described that there was a *"total lack of resource in primary care to do anything other than firefighting".*

It is likely that this will translate to a lack of time and resource to partake in activities that can have a longer-term positive impact on the practice, it's staff and it's patients. An example of this was described as the little time and resource support to redact patient records. One GP raised concern that patients having full access to their records may "*generate more time pressure to explain data entries"*.

It is not only the use of outputs that requires time and resources but also having the ability to consider requests for research and planning. Interestingly, whilst time was a recognised limiting factor, 53% agreed that they could still consider requests to be involved (n=57), whilst 22% did not (n=24).

5.3.2 Opportunity: Practice culture

Although not always described as culture, ways of working, communication and leadership were common factors which appeared to influence attitudes to data. One respondent described this as facilitating that “staff know about ‘the development’, they know what it means, what to do, the potential impact”.

5.3.2.1 Leadership and direction

The importance of having clinical leadership, a partner in the practice who is bought into data use and sharing was regularly described. This was felt to be further strengthened by a practice manager who is supportive and capable in the use of data. However, when this balance was not struck it could be a barrier. One clinical pharmacist described, *“The GPs were really keen for me to proceed [supporting the practice and having access to practice data]. I had a number of practice meetings with them. Essentially, it was the practice managers who were putting the stops on. I think in the end, after three months of trying, I ended up finding another GP practice who were part of the Trust and were happy to allow me access to do my job”.*

The leadership and direction within a practice was believed to impact on the culture and how data sharing fits within standard ways of working. Of the primary care professionals surveyed, 51% agreed that their practice has a culture where data use and data sharing is discussed (n=54). When this is explored a little further, only 11% of professionals strongly agreed that this was the case.

To probe more about whether there is a collective understanding about how practice data is used, primary care professionals were asked whether their practice participates in data sharing for research projects, including with RSC, CPRD, UK Biobank or similar. Within our survey, 39% of respondents said ‘yes’ (n=42), 37% said ‘no’ (n=40), and 23% said ‘I don’t know’ (n=25). When this was cross analysed with their role, of those that responded ‘I don’t know’, 28% were GP partners (n=7) and 56% were ‘salaried or other’ GPs (n=14). This was also reflected in our engagement where salaried GPs were less likely to know whether their practice participated in research and surveillance databases such as these.

5.3.2.2 Maturity of the data ecosystem

The maturity of data ecosystems across primary care are diverse. It was hypothesised that those who are more familiar with data, its use and application will have different views to those who are less familiar. Those working in practices where data was regularly discussed and used to shape and inform decision-making, were more comfortable with data sharing processes. An insightful comparative from a clinical pharmacist described the experience of moving from a PCN with a well-developed data culture to one which was less developed, *“the development in PCNs is very much varied, with some being much more developed and some areas being much more proactive in terms of sharing data or being comfortable with the sharing of data or having those agreements in place to be able to do so. One of the concerns that I've had moving [to a new area] is that we're quite a lot further behind, and that's really hampering some of the work that we're doing, and it's quite a big frustration”.*

Interestingly, a discussion with a paramedic from a practice with a particularly positive and developed data ecosystem described how they were encouraged to use data to audit and research for best practice. In that instance of a mature data ecosystem, time and resources to support was believed to be less of an issue as they *“will source funding, or even pay themselves* *for staff to do more training. But to be able to request any kind of training you've got to be able to evidence it's necessary – that's where the data comes in".*

It is not just the maturity of the practice data eco-system which is important, but that of the wider heath community. There is a reflection that the legal responsibilities associated with information governance have historically contributed to the organisational silos. One of the challenges of those working to integrate care and its records has been working to overcome these silos, gaining consent from across organisations involved in the local ecosystem.

5.3.3 Opportunity: The COVID-19 pandemic

Since the COVID-19 pandemic, the importance of data use and sharing has become more evident. In fact, the outputs from data sharing in primary care have been showcased in the mainstream media and public health arena (to inform vaccination or shielding lists). However, this has also exposed the issues in data recording and missing data. It was described through our engagement that patients did not question how they ended up on the shielding list, which could reinforce the sense that patients assume that information is joined up and if they are benefiting from it, then they are comfortable. However, one GP described that a local supermarket contacted a patient directly to offer a shopping slot as they were on the shielding list, but the GP believed that this was a step too far.

The response to COVID-19 pandemic saw an initial "huge shift" in GPs in seeing the importance of clinical research and wanting to support research such as the PRINCIPLE trial and by signing up to RSC. RSC membership increased from 500 practices in 2018 and is now at 2,000 practices. This suggests that the COVID-19 pandemic has supported uptake in data sharing initiatives.

The pandemic has shifted views on information governance in areas such as text messaging. Prior to COVID-19, some DPOs were very restrictive on when a text message could be used as it was thought to be marketing – sometimes even to invite people to flu clinics. Whilst it is still not appropriate to use text messaging to invite people to research studies (unless they have consented), it is now being better utilised to engage with patients.

There was some nervousness, however, that the reduced bureaucracy granted from the COVID-19 pandemic will soon be lost and whether gains in integration may follow. For example, an exemption was granted to email care homes regardless of whether they had NHSmail or not. With that exemption coming to an end, there's been a push from some professionals to address this and maintain data sharing principles in providing quality care for patients.

5.3.4 Opportunity: Topography

There are opportunity factors linked to the topography of the practice such practice list size, number of health care professionals, geography and deprivation. These can impact on the ability to protect time and affect organisational or professional dynamics. In this study, there was an observation that the workforce profile within a practice may influence engagement in data use and the maturity of the data ecosystem i.e. a business manager or professional with interest in research.

Another interesting observation was that there appeared to be a different appetite for data use in training or research practices. Those practices described the excitement and expectation for FY2 and Registrars to undertake research, quality improvement projects and audits within the practice to contribute to continual improvement.

Through this qualitative study, there were little conclusions that we could feasibly draw linked to the practice topography. However, this would be an area of future research that may hold value and learning. For example, analysis of opt out data[28], as illustrated in Figure 5.5 and Figure 5.6, suggests that those practices in the least deprived areas experience a higher level of patients opting out of sharing their data, compared to those practices within the most deprived quintiles. A higher opt out rate can also be observed in those practices with the smallest registered practice populations.

Figure 5.5: Opt out rate by deprivation decile

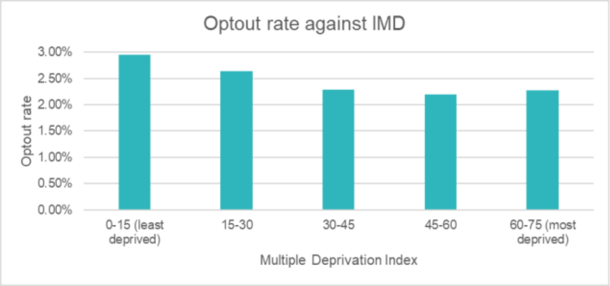
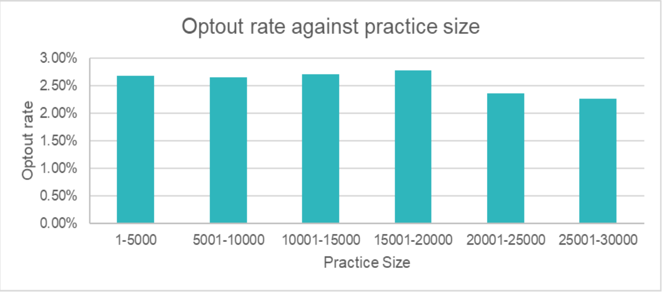


Figure 5.6: Opt out rate by practice list size



Further analysis would be required to understand the correlation between those practices within the most deprived areas and their practice list size, alongside the factors which make patients more or less likely to opt out and the influence that a practice and its culture can have on this. One stakeholder described how when registering with a new practice, they were handed a pack of information to complete which included an opt out form with little supporting information. This is something which may be common practice and can sub-consciously effect the behaviour of patients on this issue.

5.4 Dynamic nature of these factors

Whilst each of these factors have been described in turn, it is important to remember their dynamic nature and how these interact to create the behaviours and attitudes which primary care professionals may experience.

In Figure 5.7 below we have outlined two scenarios about how these could manifest in practice. Whilst we recognise that these are a simplification, it provides an insight as to how these factors come together to influence the attitudes of primary care professionals.

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[28] [MI] National Data Opt-Out - NHS Digital

Figure 5.7: The dynamic nature of these factors

5.5 Variation across roles and devolved nations

As described in this section, there has been a lot of commonalities in the factors described by different roles working within primary care. Variation has been evident where those working in primary care additional roles[29] described less anxiety towards information governance responsibilities. This may be influenced by the nature of their work which means they already utilise different clinical systems depending on the location in which they are working, which may also be across a number of practices, a PCN or ICS. This is in contrast to the contractual obligations held by GPs which influence their attitudes in this area. There were anecdotal examples as to where this has manifested as a barrier to data use by these additional roles, limiting their role. Those working within these additional roles were also able to provide interesting reflections on the importance of practice culture, bringing their experiences of working across practices and PCNs.

Interestingly, when describing the use of outputs from data use, those working in additional roles tended to describe this as being for direct care or care coordination, as opposed to research or planning activities, although some references were made to population health and

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[29] The Additional Roles Reimbursement Scheme (ARRS) allows PCNs to appoint to advanced practitioners in primary care. This spans a range of roles including, but not limited to clinical pharmacists, community paramedics, social prescribing link workers, care co-ordinators and health and wellbeing coaches.

public health management benefits. This may be due to the specific roles of those engaged with.

This study has been cognisant of the different structures and systems that exist across England and the devolved nations of Northern Ireland, Scotland and Wales. At the roundtable in which emerging findings were discussed, there was a recognition that it would be helpful to map the information governance frameworks, the databases in which data is available and the governance process which enables access, to understand where variation exists.

GPs across the four nations all described very similar factors, describing these in their own context. For example:

- In Scotland and Wales, care is the responsibility of Health Board and prevents competition from Alternative Provider Medical Services (APMS) Providers, which provides a *“slightly different mood music”* to these factors. Challenges in Scotland were highlighted however as this means that IT hardware and software (such as virus protection) is the responsibility of the Health Board, yet GPs must operate and discharge their information governance duties using these.
- In Scotland, QOF was retired in 2016 and there has been a feeling that this has enabled focus to be placed on locally driven quality improvement approaches, supported by local intelligence support teams.
- In Northern Ireland, GP Intelligence Platform (GPIP) provides a trusted research environment for research but the information governance safeguard in place makes it challenging to access and use.

5.6 Testing the hypothesis

This study has also contributed to testing the validity of the following hypothesis: *Identifying positive benefits and minimising perceived risks, increases primary care health professionals’ willingness to advocate for and support the use of high-quality health data.* Key findings from the engagement of this study in response to this hypothesis are as follows:

- A common theme from many working across primary care was that data use is needed to provide the best quality patient care possible; both in terms of care and care coordination but also for research and planning for future treatment and services. Benefits include the improved quality and safety of patient care, alongside the efficiencies achieved by reducing fragmentation and duplication. The useful outputs which can go on to shape patient care, local planning and research are also important incentives for participation. These are motivating behaviour conditions.
- Across the spectrum of primary care health professionals engaged with as part of this study, there is a strong sense of responsibility for the safeguarding of patient data. Whilst our survey results suggest that nearly all professionals understand the requirements, processes and responsibilities associated with their role, GP stakeholders have described to us the challenges in navigating these, accessing support where this is needed and the fear that this can generate. These risks are associated with capability, motivation and opportunity factors. The following conditions are considered to minimise these perceived risks:
  - Being assured of the purpose for which data is being used, including to advance quality of care or treatment
  - Being assured as to who will have access to the data
  - Being assured as to who the beneficiaries of the use of data will be
  - Being assured that data will be appropriately safeguarded. For research and planning this may include de-personalising or anonymising data, gaining consent and utilising TREs.
  - Being assured that appropriate data sharing protocols and agreements are in place.

- Whilst the majority of survey respondents agreed they were comfortable sharing data across the practice for care and coordination and research purposes, this level of comfort decreased the more widely the data is to be shared. A greater proportion of respondents were comfortable with sharing data for research purposes across the PCN, ICS and more widely within the NHS, compared to sharing data for care and coordination. This is likely to be due to the conditions in which the data is being shared, including the anonymisation of data where appropriate.
- Nearly all participants in this study have advocated for the use of data but we have heard many describe a ‘trade off’ between benefit and risk.
- An example of some of the qualitative comments which reflect this include:
  - *“I am strongly of the view that usually more harm can come from not sharing data than by sharing it”.*
  - *“I think if you ask the individual GP you know do you do you agree with the with the statement ‘data saves lives’, you know they will. [If you then said] OK, well, give me your data. No, absolutely not. And so there a disjunction here between our belief that the data should be available in shared and how we go about doing that and keeping everyone safe”.*

This section of the report has highlighted the range of factors which can affect the behaviours of primary care professionals with regards to data use. Understanding these conditions and factors can enable programmes of change to better plan, communicate and consult with primary care stakeholders. The final section of the report outlines opportunities to shape these behaviours for the future.

6 Overcoming barriers

Highlights

There is a recognition that the primary care data ecosystem continues to evolve, with the COVID-19 pandemic highlighting the importance of data use and sharing across both patients and professionals and with system providers seeking to enhance to technical capability and integration of systems. The publication of the *Data Saves Lives* strategy, alongside developments such as GPDPR and the accelerated programme for access to full historical GP records continue to push progress in this area; but it is important that primary care professionals are engaged in these developments.

Understanding these factors which drive behaviours and attitudes can enable programmes of change to better plan, communicate and consult with primary care stakeholders. This section of the report describes interventions which have the ability to overcome the barriers outlined in section 5, seeking to increase both the engagement and empowerment of primary care health professionals in the use of health data. This includes increased or enhanced training and education, enablement activities to provide support and foster trust, as well as considered and consistent communication with the public, patients and primary care workforce.

It is recognised that work to progress some of these opportunities is already underway as part of the implementation of *Data Saves Lives*, the *Long Term Plan* and as part of local work which is being undertaken in primary care. A practical checklist has been developed to support those planning or implementing a data related initiative in primary care.

The context in which data is being used in primary care continues to evolve, with the COVID-19 pandemic highlighting the importance of data use and sharing across both patients and professionals and with system providers seeking to enhance to technical capability and integration of systems. The publication of the *Data Saves Lives* strategy, alongside developments such as GPDPR and the accelerated programme for access to full historical GP records continue to push progress in this area; but it is important that primary care professionals are engaged in these developments. This final section of the report outlines opportunities to overcome the barriers, seeking to increase engagement and empowerment of primary care health professionals in the use of health data.

6.1 Interventions

Engagement from this study has identified a range of factors which effect the capability and motivation of primary care professionals to use data, alongside the opportunity they have to do this. The COM-B framework provides a behaviour change wheel to categorise interventions which can change these behaviours; including education, enablement and environmental restructuring for example. However, through discussion with stakeholders it was considered that a more inclusive and consultative approach is required to overcoming some of the barriers discussed. This section therefore describes some of these interventions, then providing a checklist for those planning or implementing a data related initiative in primary care.

Insights into potential interventions to address these barriers were generated through stakeholder interviews and survey responses where the following question was posed; *“Do you have any ideas about actions that could encourage you and your colleagues to have trust in and support the sharing and use of health data?”.*

Enhanced or increased education and training, which was commonly described to achieve:

- Improved clarity on information governance processes
- Improved skills to maximise existing systems and processes
- Improved quality of data coding and record curation
- Improved analytical skills.

This was thought to be achievable through training and education programmes, both national or more targeted as well as ‘hands on’ with practices. Webinars and activities also contribute to continuing professional development (CPD) and widely available resources from organisations such as RCGP or NIHR to support practices were also highlighted. Considering feedback around time and resources, protecting time for training and education was considered to be important as well as undertaking after action reviews and sharing lessons learnt when appropriate.

Through engagement there was some discussion about the extent to which information governance and data use was taught as part of medical education. It was felt by many that this could be strengthened, particularly in light of the advancement of the data and digital agenda.

Some described that the infrastructure of clinical systems should be informed by end user requirements which that could engender trust in data use.

Moreover, the homogeneity in data coding was commonly described as a barrier. In responding to this, some suggested that training on coding and the importance of record curation would be of benefit for clinical staff. However, others described a need for **improved delegation** to administrative teams who have greater expertise in coding, also releasing clinical time. It was described, *“One of a GP's most important (but largely unacknowledged) role is the curating of a patient's notes… we lack a consistent approach to how we document and code our consultations. This makes auditing and the extraction of useful data for research difficult. I would like to see GPs spend less time on administrative tasks that could be delegated and more time, as a college and as a profession, focusing on more rigour and uniformity in how we document, code, and share patient records”.*

Enablement activities to address some of these barriers were also described. Examples of these included:

- Easier access and visible support from expert resources such Data Protection Officers or Caldicott Guardians
- Sample templates for data sharing agreements and Data Protection Impact Assessments (DPIAs) that could be adapted
- Support to further enable clinical leaders to foster trust in data use and some of the issues described in this study
- Engagement and peer learning with professionals in practices with a mature and successful data ecosystem.

Improved communication with the public, patients and primary care workforce was considered to be important. As part of this:

- It is important that there is consistency in this communication both across stakeholder groups as well as across primary care more generally. For example, some GPs have highlighted that practice statements vary considerably in whether patient data is used for research purposes, which creates inconsistency even within a single PCN
- Communication should demonstrate the value and benefits of data sharing, not just for direct care or short-term service improvement projects, but also for longer-term research or population health management approaches
- Embedding co-production with primary care staff was considered to be important when considering use of data beyond their practice reach or shaping developments.

In areas much more challenging to effect change, a number of respondents did highlight a desire to reduce the political influence on the system. One respondent commented *"currently the NHS is too politicised. There are already too many instances where NHS data has been 'leaked' to private industries, currently do not trust those at Exec level to safeguard data as they are too close to the government who are trying to control NHS data. This is also not a 'view' but have seen instances where this has happened"*. In a similar way, seeking to reduce the liability and professional implications should breaches occur was also highlighted as a suggestion.

The evolving data and digital landscape provides opportunities for these interventions to be embedded and many are already being considered as part of the implementation of *Data Saves Lives* and the *Long Term Plan*. For example, as mentioned in section 1.2.2, strengthened communication with health professionals and the public about GPDPR is an important priority before the data extraction framework is embedded. Similarly, in setting out the commitments to simplify information governance arrangements, DHSC describe the need for giving staff *"clear, unified, simple guidance on what they can share, who they can share it with, and for what purpose. We need to change the culture in which the rules are seen as an insurmountable barrier to data sharing, in which the safest option is not to share data even when this is to the detriment of care".* Other commitments in this area include a one-stop shop for help and assistance, guidance and advice, fit-for-purpose rules around different types of data (such as pseudonymised), so that staff can clearly understand rules around the use of data, a national Information Governance Strategy to address training for frontline staff as well as reviewing tool kits and language to bring into line with simplification work.

6.2 Checklist

For primary care professionals to be engaged and empowered in using data, it is important that they are consulted and considered in the design and implementation of data-related initiatives.

The findings from this research have been used to develop a checklist for those planning or implementing a data-related initiative in primary care. This practical tool will allow users to proactively and systematically assess the range of factors which will shape primary care professional's behaviours to the initiative. The checklist:

- Is structured around the conditions of capability, motivation and opportunity and the factors identified through this study
- Provides an insight into the questions that a primary care professional may be considering
- Outlines a set of questions for programme stakeholders to proactively consider as part of the planning and implementation of their initiative.

The checklist is provided overleaf.

Condition	Questions a primary care professional may have	Checklist for programme stakeholders
Capability	Do I understand and am I comfortable with the information governance implications of the initiative and any actions that are required of me? Does my clinical system have the capability to do what is being asked? If additional functionality is being developed, am I able to use this? Where can I access support or training?	1. What will be the information governance implications of the initiative for primary care professionals? Have these been considered and discussed with relevant primary care and legal professionals? 2. How will these implications be communicated to primary care professionals? 3. Are there tools you can supply to help professionals navigate these implications (such as user-friendly data protection impact assessment templates for example)? 4. Do existing systems have the capability to fulfil the requirements of the initiative or is additional functionality required? 5. Are there any changes required in the ways of working? 6. How will the above be communicated with primary care professionals? 7. Is additional training required? Who will provide this and how can professionals access this? 8. Where can primary care professionals access support if needed?
Motivation	Do I understand the purpose and need for the initiative and what the benefits will be? Do my colleagues working in primary care also understand this and do they have any concerns? How are my patients being made aware of this initiative? Are there any implications for the practice from this communication with patients?	9. Have the benefits of the initiative been articulated? 10. Have these been considered and discussed with relevant primary care professionals to ensure these benefits are comprehensive and that there is ownership from the primary care community? 11. Do primary care professionals understand the initiative, it's purpose, scope, who the data will be shared with, how it will be treated and how it will be secured? 12. Have any concerns been raised and discussed with primary care professionals? 13. What opportunities are there for practices or primary care professionals to provide ongoing feedback about the initiative? 14. How have the public been involved in this development of this initiative and are their concerns understood? Has a public facing communication plan been developed for this initiative? 15. Has the timing of the implementation of this communication plan been considered to ensure that primary care professionals and practices are prepared and able to respond to arising queries?
Opportunity	What will be the resource implications for my practice or PCN? How does this initiative align with other developments that I know are underway, both in terms of scope and timing? Is anyone leading this work locally so that we can understand more about lessons learnt?	16. Have the resource implications of the initiative on primary care been considered in consultation with primary care professionals? 17. Is there the opportunity to provide support to mitigate against resource implications? 18. Are there any other initiatives or primary care priorities which need to be considered in the planning and implementation of this initiative and its timing? 19. Are clinical leaders across ICS, PCN and practices aware and engaged in the initiative? How best could they influence local stakeholders? 20. Could peer learning be utilised in the roll out of this initiative?

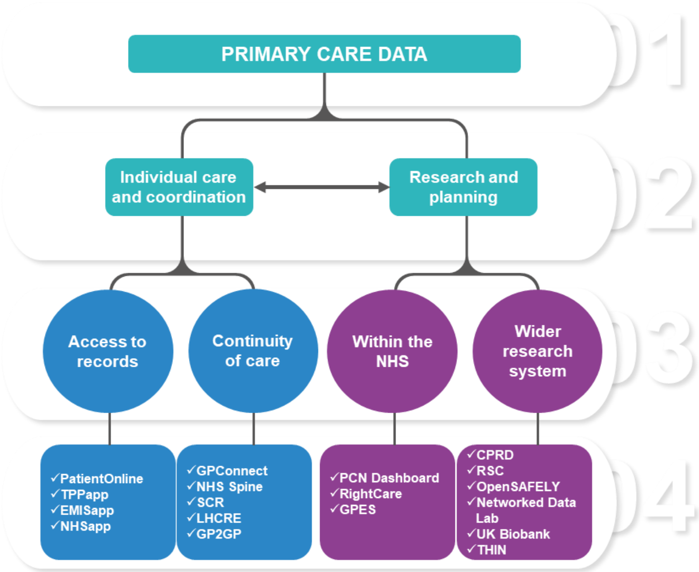
A. Literature review

A.1 Systems and processes which enable data use in primary care

It is widely established that data use in primary care has two key purposes:

3. Individual care and coordination
4. Research and planning.

In this section, we delve deeper into these themes and describe the current systems in England which support these ambitions.



A.1.1 Individual care and coordination

A.1.1.1 Patient access to records

Platforms for providing access to online records have progressed greatly in recent years, with examples such as Patient Online. Clinical system providers such as EMIS and TPP have developed apps for patients to access their medical record.

Early work suggested that providing patients with access to their electronic health records may improve quality of care by providing them with their personal health information and involving them as key stakeholders in the self-management of their health and disease[30]. A more recent systematic review found that patient access to their own record resulted in improved health outcomes, better general adherence, and medication safety[31].

There appears to be strong public support for access to full records, where work from the National Data Guardian found that 65% of adults believed it to be important. One of the key functions for wishing to have access to records was the ability to check the accuracy and have

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[30] Promoting preventive care with patient-held minirecords: A review - ScienceDirect

[31] Impact of providing patients access to electronic health records on quality and safety of care: a systematic review and meta-analysis (bmj.com)

sight of what was being held on the system[32]. Interestingly, a survey of GPs described one of the concerns that they had of online access was that the patient will disagree with the data in their record[33].

It seems clear that there is still some way to go in having primary care staff advocate for the widespread use of online access records. Primary care clinicians have regularly described concern associated with access to records causing undue worry and stress for patients, often due to trying to interpret the content without professional support[34]. Along those lines, clinicians often use the record to add notes of differential diagnoses and internal prompts which may lead to unnecessary distress for patients[35]. This also suggests that there would be the requirement for data cleaning in the 'back stage' systems before they could become 'front stage'. Access to records could also lead to supply-led demand, where one study found that having online access to records and clinicians was associated with an increased use of clinical services compared with those patients that did not have such access[36] . Little work has been done to capture views and attitudes of primary care staff on access to records beyond GPs. Nevertheless, there was a strong belief amongst health professionals more generally, that access to records could result in improved data quality and more integrated data use.

A.1.1.2 Enabling informational continuity

Continuity of care is a core value in primary care and comprises of three strands: relational, managerial and informational continuity. Most relevant here is informational continuity, which can be described as access to accurate, up-to-date, patient records. The emphasis placed on informational continuity has become even greater with the complexities in the how different parts of the health system talk to one another, for example through PCNs, ICS and out of hours services.

Informational continuity has been found to be of significant benefit when patients are unable to recall or communicate medical details to the level of detail required, for example through cognitive disorders, language barriers or simply that medication names can be difficult to remember and pronounce. Interesting, there are misconceptions in the public sphere about how joined up data linkages are in healthcare. For example, the public deliberation by One London highlighted that there was an assumption that data and notes held in general practice were accessible to other services[37]. This assumption was linked to a fundamental expectation that relevant information would need to be accessible to prevent mistakes which could compromise patient safety.

In this era of advancing technology, we have become accustomed to speedy access to information at our fingertips. It feels intuitive that patient data also moves beyond less secure methods of access such as post and fax. As a result, a number of different platforms have been developed to support data access for individual care and coordination. We go on to describe some of these in more detail.

NHS Spine is a repository which allows data to be used securely through local and national services, such as the Electronic Prescription Service, Summary Care Record and the e-Referral

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[32] National Data Guardian (2020) Annual Progress Report 2019-20

[33] Getting started with online access - RCGP

[34] Patients' online access to their electronic health records and linked online services: a systematic review in primary care - PubMed (nih.gov)

[35] Patients' access to their electronic record: proceed with caution | British Journal of General Practice (bjgp.org)

[36] Association of Online Patient Access to Clinicians and Medical Records With Use of Clinical Services | Electronic Health Records | JAMA | JAMA Network

[37] Public-deliberation-in-the-use-of-health-and-care-data.pdf (onelondon.online)

Service. This has been developed and maintained through NHS Digital and the Digital Delivery Centre.

GP Connect is a national interoperability platform which facilitates connectivity between the Spine and different electronic health record systems. For example, data held on EMIS can be accessed by authorised staff in practices who use SystmOne. GP Connect provides the means to access health records and data.

Beyond just health records, GP Connect enables appointment booking across different IT systems – promoting the right care at the right time in the right place. For example, GP practices can book appointment for patients into extended access hubs and NHS111 can book a patient directly in for an appointment at their local practice. During the Covid-19 pandemic, GP Connect was updated on EMIS and TPP GP clinical systems to meet the operational requirements of the Covid-19 Clinical Assessment Service (CCAS). GP Connect has shown to be adaptable and responsive to providing seamless integration and improve appropriate access to care.

The Summary Care Record (SCR) contains what is believed to be the most important information in the patient record. This includes data about current medicines and allergies in a bid to provide the safest care by reducing prescribing errors and reducing delays in urgent care. Some questioned the value of such paucity in data to provide quality care. More recently, additional data has been included to the SCR to incorporate significant medical history, immunisations, anticipatory care and end of life information. To support the improved flow of information and care through the Covid-19 pandemic, a temporary inclusion to the SCR was made to include Covid-19 specific codes in relation to suspected, confirmed, Shielded Patient List and other Covid-19 related information.

Access to view the SCR (plus additional information) is granted to health and care staff, including NHS111, 999 and A&E departments. Community services such as pharmacy can also view this record. This is supported by the interoperability of GP Connect and data repository in the Spine. Patients are able to view their SCR through the NHS App, clinical provider apps and Patient Online.

The Local Health and Care Record (LHCR) programme has started work to create integrated care records across GPs, hospitals, community services and social care. In 2018, five regions were selected to receive funding to build on existing local leadership and accelerate the compliant, secure and ethical use of information to improve patient care locally, which could go on to develop the blueprint and help spread benefits more rapidly across England. These exemplar sites are testing the approach whilst adhering to fundamental standards such as the information governance framework and the technical, data and interoperability standards.

Regional areas have focussed efforts on developing their own record network. A good example to highlight is the work of North East and North Cumbria Integrated Care System in developing the **Great North Care Record**[38]. Since March 2020, staff working in hospitals, GPs, mental health, out of hours, ambulance and adult social care have access the same Great North Care Record. They have exceeded previous views of GP records with upwards of 200,000 views each month and over 5000 unique users. The uptake is growing month on month as more frontline staff can access data for care and coordination[39].

GP2GP is system which enables access to a patients' detailed record when they move practice. This has been shown to provide a quick transition between the old and new practices, where the records are available directly after registration – a much more efficient and secure route

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[38] Home - Great North Care Record Great North Care Record

[39] What do health and care professionals think about accessing the Great North Care Record? - Great North Care Record Great North Care Record

compared to the transfer of paper records in the past. This lays the foundations of informational continuity of care, where patients don't have to recount their entire medical history and increased safety, particularly in prescribing due to access to previous medications and allergies.

The uptake for GP2GP has been impressive and well-embedded within primary care; 99% of practices are on the system and it has been used to support access to around 8 million patient records since 2007.

It is important to recognise that whilst many of these systems have been established, designed and delivered independently of each other, there are a number of core principles that are consistent in each approach. They all set out to provide quality care by reducing duplication of effort, avoiding waste and ensuring that information collected at the point of care is maximised in a secure and safe manner.

A.1.2 Planning and research purposes

In creating efficiencies and better treatments in the health service, continual reviews and improvement studies are being undertaken. The success for much of this planning and research is dependent on the access and use of data.

The scale of planning can vary; undertaken at service or practice level, PCN or ICS or more widely. The planning of services can consider the health and needs of the local population and uses this to determine the scope and size of services that will be needed; ensuring that the appropriate funding and resources can be put into place. At a more local level, this may be more focused on understanding and planning for likely demand. It is also through this process that patient outcomes can be understood, and services shaped to ensure that care is safe and effective. In planning services and care, the NHS often partners with external organisation to measure effectiveness and identify areas for improvement.

Research plays a crucial role in providing a greater understanding about disease or illness and advancing current treatment regimes. It is thanks to access to data and its use in research, that we are able to treat and manage conditions in a much more effective way than we were able to in the past. Data is used to identify risk factors for disease and its severity, such as age, gender, ethnicity, where patients live, or another health problem like high blood pressure or obesity. The importance of this information was brought to light during the Covid-19 pandemic which allowed the most vulnerable groups to be identified and shaped vaccination priority strategies. Research involving medicines are also key, where they can evaluate side effects or risk factors associated with certain medications and monitor effectiveness of new treatments. Often this work is led by pharmaceutical companies or other commercially funded bodies, which use patient data for research purposes. Through data use, technology companies have been shown to support remote health monitoring, develop health-related apps and improve software for diagnostics.

In this section, we go on to describe some of the key systems and processes which are in place to support research and planning, both within the NHS and in the wider health and research sphere.

A **dashboard has been developed within the NHS to support PCNs** understand their local population health priorities and the benefits that they are delivering. Held within NHS Viewpoint, the dashboard includes data on performance and achievement for the Investment and Impact Fund indicators, as well as PCN service delivery and progress with recruitment. It is a tool which is open to all PCNs and provides a national comparison.

NHS RightCare is a programme committed to reducing unwarranted variation to improve people's health and outcomes and reduce inequalities in health access, experience, and outcomes. To do so, staff from the NHS Right care programme work with local teams to:

- Diagnose the issues and identify the opportunities with data, evidence and intelligence
- Develop solutions, guidance and innovation
- Deliver improvements for patients, populations and systems.

NHS RightCare focuses on a number of different pathways including epilepsy[40], community rehabilitation[41], frailty[42] and COPD[43]. This allows comparisons to be drawn to systems between demographically similar geographies, culminating in dashboards which compare Clinical Commissioning Groups (CCGs) with another 10 CCGs which were deemed to be similar in topography. In translating this benchmarking activity into service transformation, NHS RightCare has delivery teams to share evidence-based best practice and facilitate local improvements.

The **General Practice Extraction Service (GPES)** is a centrally managed, primary care data extraction service within England[44]. GPES data extracts contain both patient-identifiable and anonymised data. This happens within the NHS to support quality measures through the QOF and is the gateway for use of data from wider bodies within the health and research sphere. Should wider groups, such as academia, research bodies or commercial companies, wish to use this data they must adhere to the standardised process through the Data Access Request Service (DARS). This is reviewed by the Independent Group Advising on the Release of Data (IGARD) who considers all requests for dissemination of confidential information, as defined in Section 263 of the Health & Social Care Act. This process has been agreed with the BMA and the RCGP, with support from the National Data Guardian (NDG). Organisations approved to use this data will be required to enter into a data sharing agreement with NHS Digital regulating the use of the data.

To support the response to the Covid-19 pandemic, NHS Digital was legally directed to collect and analyse healthcare information about patients from their GP record[45]. This was facilitated through the GPES, with support from the BMA, RCGP and the NDG. During this time, the same oversight and assurance processes were in place and DARS for Covid-19 related research and planning were prioritised.

Clinical Practice Research Datalink (CPRD) is a UK Government research service jointly supported by the Medicines and Healthcare products Regulatory Agency (MHRA) and the National Institute for Health Research (NIHR) to promote healthcare research and drive innovation through use of UK patient electronic health records. CPRD was one of the first platforms to provide routine record linkages between primary care data and a range of health-related patient datasets. It covers the four nations of the UK and includes 16 million currently registered patients. CPRD uses only anonymised data for research purposes and this has been the source for over 2,700 peer-reviewed publications investigating drug safety, use of medicines, effectiveness of health policy, health care delivery and disease risk factors.

To contribute to the CPRD database, GP practices register their interest and data is extracted directly without additional manual input. At present around 20% of GP practices are signed up to contribute to the data pool for research purposes. Aside from public health interest, CPRD describe additional benefits to primary care professionals and include[46]:

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[40] NHS RightCare » Epilepsy toolkit (england.nhs.uk)

[41] NHS RightCare » Community rehabilitation toolkit (england.nhs.uk)

[42] NHS RightCare » Frailty (england.nhs.uk)

[43] NHS RightCare » Chronic Obstructive Pulmonary Disease (COPD) Pathway (england.nhs.uk)

[44] General Practice Extraction Service - NHS Digital

[45] Coronavirus (COVID-19) response transparency notice - NHS Digital

[46] CPRD information flyer

- Ensuring their patient population is represented in research evidence informing clinical guidance and best practice
- Earning extra income for the practice by taking part in simple questionnaires and clinical studies
- Receiving regular practice-level prescribing and patient safety QI reports including patient case-finding and national practice benchmarking
- Case reviews from QI reports, questionnaires and research count towards annual appraisal and revalidation.

Should researchers wish to access data held on the CPRD database for research purposes, they will submit a research application and is subject to review and approval by an Independent Scientific Advisory Committee.

The **Research and Surveillance Centre** (RSC) is a collaboration between RCGP, the University of Oxford, and Public Health England. At the time of writing, data was extracted from 538 practices across England and Wales and covered over 5 million patients[47]. Access to the data held on the RSC database for research will be granted following a successful review and application process[48].

Practices can choose to sign up to be part of the RSC which will enable anonymised extraction of data from their clinical systems twice weekly. In doing so, they not only participate in the wider public health and research ambitions, but practice members have access to their own dashboard which includes feedback on data quality and comparison against the rest of the network. This individualised feedback is based around various aspects of a practices coding and can be of use for ongoing quality improvement. The RSC is supported by a dedicated team of Practice Liaison Officers, who can also support in quality improvement and surveillance beyond providing data.

The Health Foundation launched the **Networked Data Lab** Initiative in 2020 in a bid to bring together analytical teams across the UK and deliver data-driven insights on shared problems facing the health and care system. Recognising the challenges within the system, the Lab aims to create a community of analysts, with in-person and virtual links through open shared code and data products. Following a competitive process, five partners were selected for funding to support engagement with patients and the public, technical requirements, data stewardship and project management[49]. The lessons and learning which will be produced from the Networked Data Lab initiative will not only allow refinement for their own work but will likely be useful for complementing data systems. Whilst the funded initiative lasts two-years, it is likely that insights will be shared from The Health Foundation formatively[50].

Since 2006, the **UK Biobank** has built a large-scale biomedical database and research resource, which contains in-depth genetic and health information from half a million UK participants. Collecting genetic material through blood, urine and saliva from volunteers aged between 40 and 69 years old and linking this to information on their lifestyle, has generated a deeper understanding of how individuals experience disease or illness. Data use from the UK Biobank has generated over 1400 publications across the globe; highlighting that simple measures such as a simple eye test can detect those at a greater risk of dementia before cognitive symptoms occur[51]. In keeping with advancements, the UK Biobank database is

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[47] RCGP RSC Network Intelligence Observatory

[48] RSC application

[49] The Networked Data Lab | The Health Foundation

[50] Using data to tackle COVID-19: what we’ve learned at the Network Data Lab | The Health Foundation

[51] Association of Retinal Nerve Fiber Layer Thinning With Current and Future Cognitive Decline: A Study Using Optical Coherence Tomography | Dementia and Cognitive Impairment | JAMA Neurology | JAMA Network

regularly updated with additional data. Most recently, the database was linked with primary care records for the volunteers who reside in England[52]. Data was included from a wide range of medical records, including Covid-19 diagnostic tests, deaths, GP records and hospital episode (including critical care events). This will provide a unique insight into the genetic influence, if any, on the long-term impact of Covid-19.

The Data Lab at the University of Oxford focuses on using practical data sets to shape and inform care through the development of useful tools and software. Two key platforms linked to primary care data are OpenSAFELY and OpenPrescribing. **OpenSAFELY** features an open source analytics platform which holds pseudonymised primary care data of 58 million people. That data includes the full primary care GP record and linked to wider secondary care activity (hospital admissions, outpatient or A&E visits, ICU and Covid-related data). The catalyst for developing the platform was to deliver urgent answers on key clinical and public health question in the face of the Covid-19 pandemic.

The team at OpenSAFELY have developed a new model which sits within the existing clinical systems and results in enhanced security and timely access to data as they do not have to transport large volumes of potentially disclosive pseudonymised patient data. Instead, analysts can extract near real-time records inside the data centres and secure cloud environments of the electronic health records software companies.

OpenPrescribing, also developed by the Data Lab, provides insight into GP prescribing behaviour, down to the level of individual doses and brands, of individual drugs, at individual practices, each month. The aim of providing this level of information is to improve the quality, safety, and cost effectiveness of prescribing.

The **PCN dashboard** has been developed by Ardens Health Informatics and assists GP practices, PCNs & CCGs to monitor contractual activity[53]. Linking data from the clinical systems (EMIS and SystmOne), the dashboard collates and visualises activity linked to:

- Early Cancer Diagnosis which highlights referrals and diagnosis rates across practices and PCNs. This also includes screening reports which provide a greater level of detail to help identify and target at risk groups.
- Enhanced Health in Care Homes which records activity relating to MDT meetings and care plans, including treatment escalation plans, as well as routine reviews including mood, memory and nutrition assessments
- Structured Medication Reviews by clinical pharmacists and clinicians to the ‘at risk’ groups. With a greater lens, the dashboard also highlights specific activities, such as polypharmacy reviews, drug optimisation and compliance checks.

The Health Improvement Network (THIN) hosts a database of UK Primary Care data which contains pseudonymised longitudinal patient records for approximately 6% of the UK Population. THIN data aims to support developments and improvements in patient care by enabling data use amongst leading healthcare technology companies, authorities, academics and research organisations. THIN datasets have supported the publication of over 1000 peer-reviewed papers[54].

On 28 May, the RCGP and BMA urged NHS Digital to defer the introduction of **GPDPR** and communicate more fully with patients and inform them of their options regarding concerns and criticisms around the programme[55]. Since an announcement on 8 June 2021, the

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[52] UK Biobank and links with clinical record system

[53] Ardens Manager – Clinical & Contract Reporting for Primary Care

[54] Resources Hub (the-health-improvement-network.com)

[55] College update on patient data proposals – GPDPR (rcgp.org.uk)

implementation of GPDPR has been postponed from 1 September 2021 allowing for more time to speak with patients, doctors, health charities and others[56] .Currently, no action is required by GP practices or GP system suppliers to respond. Discussions are still ongoing regarding the next steps for the programme and data collection will now only begin once certain criteria have been met. Although the new system is more transparent than the existing one, it is difficult to understand how the two types of patient opt-out will be applied[57]. Media coverage on the new programme so far has highlighted the concern around the choices patients have and the difference between a Type One Opt-Out and a National Data Opt-Out. UPD have urged NHS Digital to put more resources behind actively promoting the different choices available to people. It has been recommended that to protect patient data from commercial access is to ensure all patient is held in a Trusted Research Environment, which will reduce the need to send data to researchers. UPD believe that this must become the default way patient data held, managed and accessed in the future.

Whilst NHS Digital are continuing to work on the infrastructure and communication for the project, a letter from the Minister for Primary Care and Health Promotion, Jo Churchill, sent a letter to all GP's explaining that they will not be setting a specific start date for the collection of data[58]. Instead, data collection will begin to be uploaded once the following criteria has been met:

- The ability to delete data if patients choose to opt-out of sharing their GP data with NHS Digital, even if this is after their data has been uploaded
- The backlog of opt-outs has been fully cleared
- A Trusted Research Environment has been developed and implemented
- Patients have been made more aware of the scheme through a campaign of engagement and communication

A.2 Systems in the devolved nations

Looking beyond England towards the devolved nations of the United Kingdom, it is useful to reflect where there are similarities and differences in the approach to delivering care and maturity of the data use ecosystem. The overarching principles of healthcare in the devolved nations are the same as that of England; a unified, tax-funded National Health Service, consistent professional training and governance, and an overlapping IT system supplier base. Across all of the nations, primary care continues to be the first point of contact for patients, acting as the gatekeeper to secondary or specialist services.

Whilst integration across the health and care system is the ambition for all four nations, the model of care in England is more fragmented than that of the Scotland, Wales and Northern Ireland. In England, health care remains the responsibility of national government and social care lies in the hands of local authorities, although there is a move towards integration. As of 2016, the Public Bodies Act in Scotland brought health and social care under one integrated system. Similar legislation was introduced in Wales and the Integrated Care Fund was created and facilitates collaboration across the social services, health, housing, the third and independent sectors[59]. With the longest legacy, Northern Ireland has had integrated health and social care since 1973. Therefore, the systems in place for data use for individual care and coordination may present with a different approach or success.

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[56] General Practice Data for Planning and Research (GPDPR) - NHS Digital

[57] Our perspective on the new system for GP data | Understanding patient data

[58] GPDPR September implementation date is scrapped (digitalhealth.net)

[59] https://gov.wales/sites/default/files/publications/2019-02/integrated-care-fund-revenue-capital-and-dementia-guidance-april-2019.pdf

In this section, we provide an insight into the systems which support and enable data access and use in each of the devolved nations.

A.3 Scotland

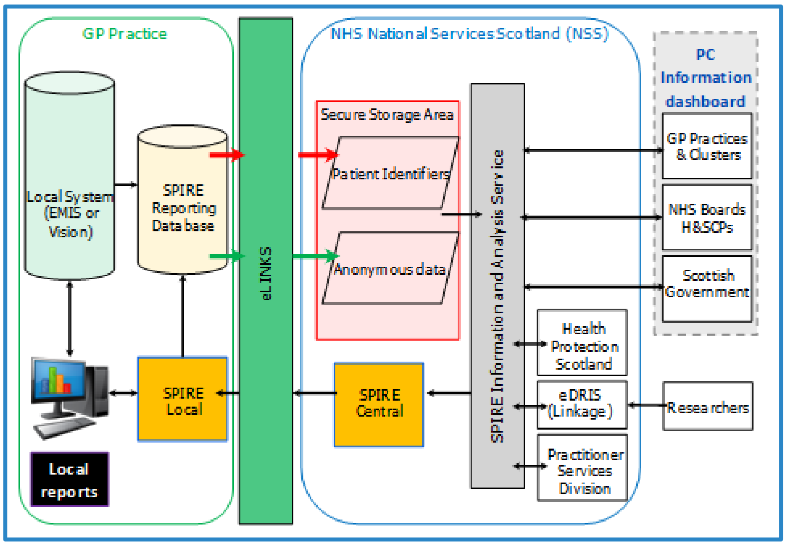
Scotland is a nation of over 5 million people, accounting for just over 8% of the UK population, and has a devolved government responsible for the administration of health and social care.

The Scottish Government Records Management Code of Practice for Health and Social Care (Scotland) 2020 was the first of its kind by bringing together Local Authorities, NHS Scotland Health Boards, General Practices, National Records Scotland and network of archivists. The code of practice sets out instruction for the use of data for individual care but also covers data processed for purposes other than direct care such as including planning and management of services and research.

Scotland made early progress with health IT, particularly in primary care, with the implementation of computerization and clinical coding having taken place over the last two decades. This has been supported by in-practice networked information systems including digital patient records, electronic prescribing, decision support, clinical communications and administrative tools[60].

One of the main tools for data use in Scottish primary care is SPIRE (Scottish Primary Care Information Resource)[61], which facilitates the management of information at a practice level, and extraction of primary care data at GP, practice, cluster, locality and national levels. The outputs and functionality of the SPIRE tool can be used for quality improvement, local service planning, public health intelligence and research with appropriate safeguards. The structural overview of SPIRE is depicted below in Figure 6.1, highlighting the extraction from clinical systems such as EMIS, secure storage at NHS National Service Services Scotland and linkages to different bodies for research and planning. The collaborative development of SPIRE in 2017, brought together a wide-ranging multidisciplinary team and encompassed a public engagement campaign to inform of opt-out processes.

Figure 6.1: Structural Overview of SPIRE



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[60] Status of health information exchange: a comparison of six countries - PubMed (nih.gov)

[61] SPIRE | Professional | Home

Through the support of Local Intelligence Support Teams[62], a number of other tools are used including:

- **Primary care information dashboards** which provide a single access point for GPs and practice staff to see health care information for their GP Practice and Cluster. Through Tableau, this can be visualised at National, Health Board or Health and Social Care Partnership (HSCP) level.
- **NSS discovery and GP cluster dashboard** which can allow users to review performance, benchmark against peers and identify areas where resources could be targeted to address local health and care needs.
- **Scottish patients at risk of readmission and admission (SPARRA)** can help health care professionals identify patients with complex care needs who may benefit from anticipatory health care, including a medicine review. SPARRA data can also be used to help plan services by highlighting groups of patients who would benefit from those services.

In an effort to undertake inclusive research studies in Scotland, the Scottish Health Research Register (SHARE) was developed. This is a register whereby citizens can consent to the access and use of their electronic health records in order to identify them as potentially eligible for research projects. The ambition is to reach 1,000,000 registrants. More recent work has expanded to GoSHARE (Genetics of the Scottish Health Research Register) where, in addition to the SHARE consent, the participants are asked for "pre-consent" for the future storage and research on spare blood samples that remain after routine clinical testing.

A.4 Wales

Wales is a nation of 3 million people and accounts for just under 5% of the UK population. The NHS Wales Informatics Service (NWIS) was established in 2010, responsible for the design, deployment and management of digital services for health and care in NHS Wales. From April 2021, NWIS was superseded by Digital Health and Care Wales (DHCW) is a new Special Health Authority with a role in changing the way health and care services are delivered.

The Welsh Clinical Portal (WCP) was one of the first platforms in Europe, to implement a nationwide system for use and access of patient data. The WCP combines different sources of information, to provide up-to-date and accurate patient records. The record originating from primary care can be accessed by professionals across the healthcare system, including secondary care clinicians, pharmacist, paramedics. The main features of the Welsh Clinical Portal are:

- Requests tests – Creates test sets, bulk order tests for multiple patients and requests tests for a patient on selected days.
- Prioritises referrals - Sorts and displays electronic referrals into levels of urgency, places them on hold, or requests more information from the GP.
- Creates patient 'watch' lists – Keeps track of patients more closely by organising patient care, similar to how shoppers sort their lists on consumer websites.
- View patient's GP record - Accesses a summary of important information held on a patient's GP record, such as current medication, recent test and allergies.
- Access results – Views diagnostic test results and reports regardless of where they are produced in Wales.

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[62] LIST Our Stories (isdscotland.org)

- Access radiology images – Views patients' x-rays, ultrasound, CT and MRI scans taken anywhere in Wales.
- View patients’ medical history – View patients' referrals, discharges, letters, outpatient assessments, clinical notes, care plans, contact lists and much more at any point in a patient's journey.
- List medication and prescriptions – Imports a pre-populated list of medicines from a patient's GP record.

The WCP is also available on a mobile app which allows for greater convenience and responsiveness. It also has a feature which allows the GP to write notes to patients on their record regarding treatment or conditions.

One of the emerging ambitions for NWIS and now DHCW is the establishment of the National Data Resource (NDR) and to maximise data use to support decision-making and planning. Given the integrated approach already in place, NHS Wales are set to be in a good position to accelerate the use of existing data to achieve better value health and care, improve health outcomes and ensure access to data and insights that will meet the needs of future generations.

A.5 Northern Ireland

Northern Ireland is a nation of 1.8 million people and accounts for just under 3% of the UK population.

Since 2013, the Northern Ireland Electronic Care Record (NIECR) has allowed care professionals such as doctors, nurses and social workers, as well as certain authorised administrative staff, to access data on patients’ medical and social care history[63]. The aim is that the NIECR support individual care and coordination, with examples of information available to be:

- Demographic data, such as date of birth
- Medicines
- Allergies
- Illnesses
- Current treatments
- Diagnostic results from laboratory or imaging investigations
- Encounter and discharge letters from various HSC systems

There are additional layers within the NIECR, including the Emergency Care Summary Record (which only contains personal details and current allergies and medication) and the Key Information Summary Record. The GP is able to decide if a patient would benefit from the generation of the Key Information Summary Record and this is most often in the case of those with long-term conditions. This record would include:

- Relevant medical history, including any long-term conditions
- Agencies involved with the patient
- Care plans
- Preferred treatment arrangements
- Resuscitation status
- Advance Decision to Refuse Treatment (ADRT) in place

Consent will be sought from the patient to generate the KIS and allow access to this information for wider health and care professionals.

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[63] NIECR_Privacy_Notice.pdf (hscni.net)

There is a recognition that this approach is still fragmented and relies on a patchwork of ageing legacy systems and digital infrastructure. To address this, a recent initiative called Encompass is being rolled out which aims to bring information together in one shared record that health and social care staff will be able to securely access, record and share information in real time[64]. The ambition is also to enable patients and carers to book appointments, review test results, and communicate with those providing their care. This will be run through a £275m deal with Epic. At the time of writing, the programme is in its Workflow Walkthrough and Configuration phase and is due to be live across the five Trusts by 2024[65]. There seems to be some ambiguity about the inclusion of when this will be live for primary care as the initial focus is on acute and community care.

Whilst the devolved nations have different systems and policies in place to support safe and secure data use in primary care, they all follow similar principles:

- Integration across systems in healthcare and social care
- Access to care records across the system
- Patient access to care records
- Safe and secure platforms for data use
- Regulatory input and policy control

A.6 Attitudes in primary care to data use

Whilst the previous section provides an overview of different systems and platforms to enable data use in and around primary care, this only paints part of the picture. There are other factors which must be considered in the implementation and use of data through these systems. These factors impact the uptake or success of each system, as well as contributing to the attitudes of professionals which enable or disable the use of data.

Our initial analysis of the literature, identifies three interdependent strands which can influence attitudes of data use in primary care, these include:

- System dimensions linked to capability
- Human dimensions linked to motivation
- Contextual dimensions linked to opportunity

A.6.1 The System Dimension

One of the initial factors for enabling the system dimension is simply having **awareness and familiarity** of the platforms for data use and access. Work from the Cambridgeshire and Peterborough CCG, for example, highlighted a relatively high awareness of data use tools for individual care and coordination; 99.5% of GPs and practice managers had heard of the SCR. Despite good awareness, only 56% of GPs and 76% of practice managers indicated that they use it[66]. These insights highlight the importance of both the awareness of the tools and how, if at all, these are used in practice.

It is interesting that over one third of GPs in the 2017 study had never heard of care.data, as it transpired to be one of the most contentious and intensely debated data use programmes in the country. Care.data set out to provide joined up records for individual care, planning and research functions, not dissimilar to platforms and tools which are in use today. However, **much of the controversy surrounding care.data was in the implementation**. The care.data

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[64] Northern Ireland signs with Epic for £275m EPR programme (digitalhealth.net)

[65] Encompass sets out on Epic journey - HSCB (hscni.net)

[66] Between "the best way to deliver patient care" and "chaos and low clinical value": General Practitioners' and Practice Managers' views on data sharing - PubMed (nih.gov)

programme struggled due to the lack of public input and **transparency in the process, timeliness to opt-out, privacy and communication**[67]. As a result, the care.data programme was suspended in 2016. These challenges still exist; a recent survey of GPs who have used digital services such as online or video consultations in the last year, highlighted that 53% believe that digital health providers need to be more transparent about what patient data they hold and how they plan to use it [68].

It is not only perceptions of data systems but their **functionality and infrastructure** that can influence experiences and therefore attitudes towards use. A recent report from the National Data Guardian identified poor infrastructure, lack of integration and system complexity as key barriers for data use. This was also associated with a lack of training or guidance on how to access and use the systems at play [69].

There are known challenges surrounding the **quality of data** that sits within primary care clinical systems and therefore, it is not unsurprising that apprehensions have been expressed on the robustness and appropriateness of the extracted outputs. However, one could argue that this may act as a case for change; to improve the interpretability and effectiveness of the output, local efforts must be focussed on increasing accuracy and completeness of the data inputs.

A.6.2 The Human Dimension

Much work has been undertaken to explore the breadth of views in the public towards data use [70]. There are a number of core themes which have been collated and include:

- Awareness
- Trust
- Transparency
- Confidence.

The relationship between the public and their own general practice is unique; work from Yorkshire and Humber shows that people have the most trust in their GP practices, followed by the NHS in general, then banks or building societies, the local council and universities [71]. Therefore, it feels intuitive that **how the public, and more specifically patients, feel about data use** will influence attitudes of the professionals in primary care, and vice versa.

There are additional complexities to how patients influence the views of those who work in primary care. Previous work has shown variation depending on who the patient is, the type of data which is used and whether this includes free-text or coded data [72] [73] [74].

More recent work has suggested that primary care professionals are more frequently discussing data use with patients and therefore suggests that patients are given opportunities to have their questions answered and express their preferences [75].

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[67] The care.data consensus? A qualitative analysis of opinions expressed on Twitter | BMC Public Health | Full Text (biomedcentral.com)

[68] GPs concerned about data collection - LaingBuisson News

[69] NDG report on barriers to information sharing to support direct care - GOV.UK (www.gov.uk)

[70] Public attitudes 2010-2018.pdf (understandingpatientdata.org.uk)

[71] Joined_Up_Yorkshire_and_Humber_2018_v2.pdf (wyhpartnership.co.uk)

[72] Should free-text data in electronic medical records be shared for research? A citizens' jury study in the UK | Journal of Medical Ethics (bmj.com)

[73] Patient data-sharing for immigration enforcement: a qualitative study of healthcare providers in England | BMJ Open

[74] Sharing patient data: competing demands of privacy, trust and research in primary care | British Journal of General Practice (bjgp.org)

[75] Between "the best way to deliver patient care" and "chaos and low clinical value": General Practitioners' and Practice Managers' views on data sharing - PubMed (nih.gov)

Whilst patient data may be citizen owned, the **GP practice has a role as the 'data controller'** for the information that they hold about their patients [76]. The processing is almost exclusively handled on the practices' behalf through clinical record systems or other third parties, however it is the practice who are responsible for the compliance to regulation and policy. Therefore, primary care professionals are in a unique position of responsibility which may influence their views.

There has been shown to be an element of **scepticism** of how data can be used[54], particularly for performance management purposes. GPs and practice managers have expressed concern about how data can be attributed to hard outcomes which are not directly linked to primary care, such as length of stay, reduction of avoidable admissions and cost reduction.

A key component of any quality improvement strategy is having a **shared purpose** and the underpinning principles apply when considering engagement with primary care professionals for data use. It is important that primary care professionals understand their role in improving care, planning and research. This is particularly important for systems such as CPRD and RSC where practices volunteer to play their part in data use for improvement.

Ultimately, the human dimension factors will go on to stimulate or cease motivation for data use. For example, the New England Journal of Medicine described authorship and publications as incentives for data use [77]. Platforms like CPRD and RSC produce reports and dashboards for those who provide access to their practice data in order to help shape their local improvement efforts and benchmark them against the national records. This is believed to incentivise participation.

A.6.3 The Contextual Dimension

Evidence in the improvement science field highlights the challenges in implementation facing primary care due to its unique context. With the mounting pressures facing staff, very few practices have access to much protected time to make system improvements. Unlike secondary care, most practices do not have a formal infrastructure that allows protected time for training and quality improvement [78]. Whilst many data use platforms are able to extract data remotely with little input required from teams on the ground, **time constraints** become more of an issue when translating the outputs into tangible changes more locally. This can go on to reduce motivation for practices to participate in data use as they are not able to yield the fruitful outputs as they are intended. This was echoed by the One London deliberation in 2019, where participants spoke of GPs not having enough time to action the results of the analysis. Therefore, if **GPs are not able to utilise the data, then the analysis would be a waste of time and money.**

One of the recurring enabling factors for more general improvements in primary care is **stable and responsive leadership**. Some of the greatest barriers in health care are the entrenched professional hierarchies, which make it difficult for staff from different professions, grades and levels of seniority to hold open and inclusive conversations. This is will likely be important when we consider attitudes towards data use; we can hypothesise that individuals who work within practices with leadership that discuss and advocate for data use will have a different viewpoint to those who do not.

The **maturity of data ecosystems** across primary care are diverse. It is likely that those who are more familiar with data, its use and application will have different views to those who are

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[76] bma-gps-as-data-controllers-under-gdpr-november-2019.pdf

[77] Authorship Data Authorship as an Incentive to Data Sharing | NEJM

[78] https://www.health.org.uk/publications/reports/quality-improvement-in-general-practice-gps-practice-managers-think

less familiar. It will be important to consider what, if any, the contextual influence of the data ecosystem has on attitudes towards data use in primary care professionals.

There are other influencing factors within the context of primary care which can enable or hinder data use, particularly dependent on **practice topography**. Challenges in protecting time and affecting organisational or professional dynamics can often be down to factors such practice list size, number of health care professionals, geography and deprivation.

It's also important to recognise that many of these factors are interdependent. For example, more deprived neighbourhoods have fewer GPs than less deprived neighbourhoods[79] and have a greater proportion of the over-55 workforce. The 2018 GP Worklife survey found that 60% of GPs over the age of 50 intend to leave direct patient care within 5 years, an issue which is likely to impact disproportionately on deprived areas[80]. Patients in deprived communities are more likely to be seen by a locum GP and therefore has implications to continuity of care[81]. Also, GP practices serving more deprived patient populations on average earn fewer QOF points and suggests a lesser opportunity to provide data quality inputs. Together, this begins to depict some of the challenges facing different practices linked to their context and how this may influence attitudes to data use.

A.7 Interventions to support data use in primary care

Following the national data opt-out service introduction in 2018, NHS Digital and the RCGP came together to collaborate on the Patient Data Choices Project. This comprised of a number of events and the publication of a toolkit with resources to inform primary care teams on the national data opt-out; building confidence for GPs to advise and inform patients (and carers) on their data sharing options[82]. This includes clarity on the role and responsibility of general practice as the data controller, webinars and links to wider resources. Specifically referenced in the RCGP Toolkit, is the recognition of the resource package developed by UPD to "support conversations with the public, patients and healthcare professionals about how health and care data is used".[83]

These interventions have been designed to overcome the known barriers to data use; informed largely by the public and the need for improvement outlined by the National Data Guardian and wider policy.

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[79] https://www.health.org.uk/publications/reports/level-or-not

[80] Ninth National GP Worklife Survey | Research Explorer | The University of Manchester

[81] Almost one-fifth of GP sessions covered by locums in deprived areas - Pulse Today

[82] Patient Data Choices Toolkit (rcgp.org.uk)

[83] Research and resources | Understanding patient data

B. Topic Guides

B.1 Interviews with strategic stakeholders

1. Strategic importance:

Thinking about your strategic priorities/ programme, how important is data access, management and use in primary care to enabling these?

2. Existing insights into attitudes to data use:

a. From your experience within this role, what range of attitudes have you experienced with regards to data use by primary care health professionals?

- Are there any areas of consensus?
- Where is there variation in views? *[Consider different primary care staff groups, geographical areas, context/ culture of practices]*
- Does the way in which data is used change these views? *[Consider purpose, anonymity, reach, policy/ legislation, access, PC platforms]*

b. What do you consider has informed this range of views?

- Thinking of those who were more constrained:
    - What were their concerns? What factors had contributed to these?
    - Were you able to overcome these concerns? If so, how?
- Thinking of those who actively used data:
    - What enabled them to do this? [Consider capability, motivation and opportunity].

c. Are there any common contextual factors you have encountered which have helped or hindered primary care health professionals in the access, management and use of data?

3. Interventions

a. What do you consider are some actions that can be taken to encourage primary care health professionals to have trust in and support the use of health data?

- Are there any examples of good practice you could direct us too? What do you believe made these successful?
- [Consider interventions targeted to capability, motivation and opportunity]

4. Engagement with primary care health professionals

In the next phase of work, we are looking to engage with a diverse range of primary care health professionals. This includes different primary care roles (GPs, Practice Nurses, Pharmacy etc), practices which work within different contexts (geography, rural/ urban, population need) and those who might have different attitudes to data use in primary care.

a. Do you have any recommendations as to who to we could involve within this? Why would they be a useful stakeholder?

- If so, could you help us by making an introduction?

b. Are there any other perspectives you think we should consider including within this review?

B.2 Interviews with primary care staff

1. Introductions, consent to recording and background

a. **Introduction** between interview and interviewee and thank them for their time.

b. Request **permission to record interview**. This is for internal use only. Responses **will not be attributable to individual stakeholders**; but rather this conversation can help to shape the review and the conversations to be had with primary care health professionals.

c. Let me provide you with some **background** to this conversation.

As you may be aware, we are currently undertaking a review for UPD (Understanding Patient Data) and RCGP (Royal College of General Practitioners) which is seeking to:

- Improve understanding of primary care health professionals' attitudes towards health data access, management and use
- Understand whether these views represent any enablers or barriers to appropriate and timely use of high-quality data (both for the provision of care and for research and planning purposes)
- Explore what are some actions that can be taken to encourage primary care health professionals to have trust in and further support the use of health data.

The project itself is a year long and is made up of a number of phases. The second stage (which we are currently in) is focused on engaging with those who work in primary care. A survey will then follow to validate findings with a wider audience, alongside a virtual roundtable discussion later in the year.

It has been suggested that you may have valuable insights to contribute and inform this review.

I have got a set of questions to guide our conversation. Some questions may not be relevant to you, in which case we can skip past these. These questions cover:

- Your role and your thoughts on data use
- Why you have those views, considering what may have shaped or informed them
- Actions or good practice which have or could encourage primary care health professionals to have trust in and support the use of health data
- Any recommendations you might have as to colleagues to involve in the engagement within this review.

Please choose the questions which are relevant to each stakeholder:

2. Background

a. So, to get us started, please could you describe to us your role in [insert name of practice] and little bit about your practice?

- And how, if at all, do you use data in your role?
- Do you have to deal with data sharing aspects or decisions in your role?
  - [e.g working with Data Protection Officer, completing or assisting in the completion of Data Protection Impact Assessments]
- Is data sharing something which is spoken about in your practice?
  - Between staff members?
  - With patients?

3. Insights into attitudes to data use:

a. From your experience within this role, how do you feel about data use?

b. What has shaped these views of yours?

- Thinking of those who were more constrained:
  - What are your concerns? What factors had contributed to these?
  - Were you able to overcome these concerns? If so, how?

- Thinking of those who actively used data:
  - What enabled you to do this? [Consider capability, motivation and opportunity]

c. From your experience within this role and working in your practice, what range of attitudes have you experienced with your colleagues? Do they share your sentiment?

- Are there any areas of consensus?
- Where is there variation in views? [Consider different primary care staff groups, geographical areas, context/ culture of practices]
- Does the way in which data is used change these views? [Consider purpose, anonymity, reach, policy/ legislation, access, PC platforms]

c. Are there any common contextual factors you have encountered which have helped or hindered you or colleagues in the access, management and use of data?

3. Benefits and risks:

a. What do you consider the benefits of data use in primary care to be?

- If views differ in your practice, why might this be? Does this differ across primary care staff groups?
- If benefits are not widely recognised, what could be done to address this?

b. What do you consider the perceived risks of data use in primary care to be?

- If views differ in your practice, why might this be? Does this differ across primary care staff groups?
- What, if any, interventions have been successful or helpful in ensuring risks associated with data use in primary care are understood? [e.g. RCGP Toolkit]

4. Interventions

a. What do you consider are some actions that can be taken to encourage you and your colleagues to have trust in and support the use of health data?

- Are there any examples of good practice you could direct us too? What do you believe made these successful?
- [Consider interventions targeted to capability, motivation and opportunity]

5. Engagement with primary care health professionals

In this phase of work, we are looking to engage with a diverse range of primary care health professionals. This includes different primary care roles (GPs, Practice Nurses, Pharmacy etc), practices which work within different contexts (geography, rural/ urban, population need) and those who might have different attitudes to data use in primary care.

a. Do you have any recommendations as to who to we could involve within your practice? Why would they be a useful stakeholder?

- If so, could you help us by making an introduction?

Close

5. Thank you and next steps

Thank you for your time today and input to the review.

If you do think of anything you would like to add, please feel free to drop me an email. Likewise, would it be ok if I came back to you with any points of clarification? Thank you.

C. Survey Questions

1. To what extent do you agree or disagree with the statement that I am comfortable sharing data for patient care and care coordination….

	Strongly agree	**Agree**	**Neutral**	**Disagree**	**Strongly disagree**
across the practice					
across the PCN (or cluster)					
across the ICS					
more widely within the NHS					
more widely beyond the NHS i.e a trusted source or 3rd party organisation					

2. Why do you hold these views? Do you have any additional detail on the question above?

3. To what extent do you agree or disagree with the statement that I am comfortable sharing data for planning….

	Strongly agree	**Agree**	**Neutral**	**Disagree**	**Strongly disagree**
across the practice					
across the PCN (or cluster)					
across the ICS					
more widely within the NHS					
more widely beyond the NHS i.e a trusted source or 3rd party organisation					

4. Why do you hold these views? Do you have any additional detail on the question above?

5. To what extent do you agree or disagree with the statement that I am comfortable sharing data for research….

	Strongly agree	**Agree**	**Neutral**	**Disagree**	**Strongly disagree**
across the practice					
across the PCN (or cluster)					
across the ICS					
more widely within the NHS					
more widely beyond the NHS i.e a trusted source or 3rd party organisation					

6. Why do you hold these views? Do you have any additional detail on the question above?

7. To what extent do you agree or disagree with the following statements:

	Strongly agree	**Agree**	**Neutral**	**Disagree**	**Strongly disagree**
I understand the information governance requirements and processes needed to share data					
The clinical systems that I work with support effective sharing of data					
The quality of data in the clinical system allows for useful and valuable outputs					
I understand my professional responsibilities for the safeguarding of data					
I feel confident in talking to patients about how their data is safeguarded					
The views of patients have some influence on my own attitudes to the sharing of data					

8. To what extent do you agree or disagree with the following statements:

	Strongly agree	**Agree**	**Neutral**	**Disagree**	**Strongly disagree**
I know how to access advice and support (from within my practice, PCN, CCG or more widely) should I have a query about the sharing of data					
I am able to prioritise and appropriately consider requests for participation in research and planning					
I have the time and resources to effectively use outputs which have been derived from data					
My practice has a culture where data use and data sharing is discussed					
It is safe for patients to have access to their own record					
I am confident in redacting patient records, where required					

9. What do you think helps or hinders data use and sharing for care and care coordination?

10. What do you think helps or hinders data use and sharing for research and planning?

11. Do you have any ideas about actions that could encourage you and your colleagues to have trust in and support the sharing and use of health data?

About you

12. What is your job role?

- Allied Health Professional
- Care Coordinator
- Clinical Pharmacist
- General Practitioner (Partner)
- General Practitioner (Salaried or other)
- Health and wellbeing Link Worker
- Paramedic
- Practice Manager
- Practice Nurse
- Other (please state)

13. Would you describe yourself as having a professional or personal interest in the use of data?

- Yes
- No
- Unsure

14. How many years experience do you have in your role?

- 0-5
- 5-10
- 10-15
- 15-20
- 20-25
- 25-30
- 30-35
- 35-40
- 40-45
- 45-50

15. Are you employed by:

- A practice
- A PCN
- An ICS or CCG
- Other (please specify)

17. Where do you work?

18.Do you hold any other roles which may have influenced your views on data use?

- If so, please describe these and why

19. Does your practice participate in data sharing for research projects, with the RCGP Research and Surveillance Centre (RSC), Clinical Practice Research Datalink (CPRD), UK Biobank or similar?

20. How old are you?

- 25-34
- 35-44
- 45-54
- 55-64
- Prefer not to say

21. What is your ethnic group?

- Asian/Asian British - Any other background
- Asian/Asian British - Bangladeshi
- Asian/Asian British - Chinese
- Asian/Asian British - Indian
- Asian/Asian British - Pakistani
- Mixed/Multiple ethnic groups - White and Black African
- Prefer not to say
- White - Any other background
- White - English/Welsh/Scottish/Northern Irish/British
- White - Irish
- Black/African/Caribbean/Black British - African

22. I identify as:

- Man
- Prefer not to say
- Woman

D. List of acronyms

A&E	Accident & Emergency
ADRT	Advance Decision to Refuse Treatment
APMS	Alternative Provider Medical Services
BMA	British Medical Association
BMA	British Medical Association
CCAS	COVID-19 Clinical Assessment Service
CCG	Clinical Commissioning Group
COM-B	Capability, Opportunity, Motivation, Behaviour
COPD	Chronic obstructive pulmonary disease
CPD	Continuing Professional Development
CPRD	Clinical Practice Research Datalink
CQC	Care Quality Commission
CRN	Clinical Research Network
CT	Computed tomography
DES	Directed Enhanced Service
DHCW	Digital Health and Care Wales
DHSC	Department for Health and Social Care
DHSC	Department of Health and Social Care
DPIA	Data Protection Impact Assessment
DPO	Data Protection Officer
EMIS	Egton Medical Information Systems
GMC	General Medical Council
GMS	Group Medical Services
GoSHARE	Genetics of the Scottish Health Research
GP	General Practitioner
GPDPR	General Practice Data for Planning and
GPES	General Practice Extraction Service
GPIP	General Practice Intelligence Platform
HEOP	Higher Education Occupational Practitioner
HSC	Health and Social Care
HSCP	Health and Social Care Partnership
ICS	Integrated Care System
IG	Information Governance
KIS	Key information Sets
LHCR	Local Health and Care Record
LHCRE	Local Health and Care Record Exemplars

LMC	Local Medical Council
MHRA	Medicines and Healthcare products Regulatory
MRI	Magnetic resonance imaging
MS Teams	Microsoft Teams
NDR	National Data Resource
NHS	National Health Service
NHSX	National Health Service User Experience
NIECR	Northern Ireland Electronic Care Record
NIHR	National Institute for Health Research
NSS	National Services Scotland
NWIS	NHS Wales Informatics Service
PC	Personal Computer
PCN	Primary Care Network
QI	Quality Improvement
QOF	Quality and Outcomes Framework
RCGP	Royal College of General Practitioners
RCN	Royal College of Nursing
RSC	Research and Surveillance Centre
SCR	Summary Care Record
SCR	Summary Care Record
SHARE	Scottish Health Research Register
SNOMED CT	Systematized Nomenclature of Medicine
SPARRA	Scottish Patients at Risk of Readmission and
SPIRE	Scottish Primary Care Information Resource
THIN	The Health Improvement Network
TPP	The Phoenix Partnership
TRE	Trusted Research Environment
UPD	Understanding Patient Data
WCP	Welsh Clinical Portal

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