



Professional  
Record  
Standards  
Body

**Better records  
for better care**

# THE CORE INFORMATION STANDARD

A report on the standard for sharing health and care information; its development, implementation and challenges

JULY 2019

## Acknowledgements

### **The Professional Record Standards Body**

The independent Professional Record Standards Body (PRSB) was registered as a community interest company in May 2013 to oversee the further development and sustainability of professional record standards. Its stated purpose in its Articles of Association is: “to ensure that the requirements of those who provide and receive care can be fully expressed in the structure and content of health and social care records”. Establishment of the PRSB was recommended in a Department of Health Information Directorate working group report in 2012.

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### **Professional Record Standards Body**

7 - 145 Great Dover Street,  
London, SE1 4YR  
[www.theprsb.org](http://www.theprsb.org)

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## Reviewers

This document was reviewed by the following people:

Reviewer name	Title / Responsibility
PRSB Assurance Committee	PRSB Assurance Committee
Helene Feger	Director of strategy, communications and engagement, PRSB
Lorraine Foley	CEO, PRSB
Martin Orton	Director of Delivery & Development, PRSB
John Farenden	Senior Programme Lead, Architecture Team, NHS England
Gareth Thomas	Greater Manchester LHCR Clinical Lead, Consultant in Intensive Care Medicine and Anaesthesia Group Chief Clinical Information Officer Senior Responsible Officer, Integrating Care Locally Programme

## Approved by

This document has been approved by the following:

Name	Date	Version
Project Board	26/06/19	0.8
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## Glossary of Terms

<b>Term / Abbreviation</b>	<b>What it stands for</b>
A&E	Accident and Emergency
AoMRC	Academy of Medical Royal Colleges
CCG	Clinical Commissioning Groups
CCIO	Chief Clinical Information Officer
CDGRS	Clinical documentation and generic record standards
CIO	Chief Information Officer
CPAG	Clinical and Professional Advisory Group
CRO	Clinical Responsible Officer
CSP	Care and support plan. Used interchangeably with DCSP
DCB	Data Coordination Board
DCSP	Digital care and support plan. Used interchangeably with CSP
EHR	Electronic Health Record
EPR	Electronic Patient Record
ETTF	Estates and Technology Transformation Fund
FHIR	Fast Healthcare Interoperability Resources
GP	General Practitioner
GPSoC	GP System of Choice
HCPG	Health and Care Professionals Group
HIG	RCGP Health Informatics Group
HIU	Health Informatics Unit (Royal College of Physicians)
HL7	Health Level 7

HLP	Healthy London Partnership
HSSF	Health and Systems Support Framework
ICR	Integrated care record. Used interchangeably with IDCR
IDCR	Integrated digital care record. Used interchangeably with ICR
LDR	Local Digital Roadmap
LHCR	Local Health and Care Record
Metadata	A set of data that describes and gives information about other data
NIB	National Information Board
NHS	National Health Service
NHSCC	NHS Clinical Commissioners
NHSD	NHS Digital
NWL	North West London
NWL CCGs	North West London Collaboration of Clinical Commissioning Groups
PID	Project Initiation Document
PRSB	Professional Record Standards Body
RCGP	Royal College of General Practitioners
RCN	Royal College of Nursing
RCOT	Royal College of Occupational Therapists
RCP	Royal College of Physicians
SCR	Summary Care Record
SNOMED-CT	Systematized Nomenclature of Medicine - Clinical Terms
SOCITM	The Society for Information Technology Management
STP	Sustainability and Transformation Plan

ToC	Transfer of Care
WSIC	Whole Systems Integrated Care

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## 1 Executive Summary

People want to see the benefits that digital information sharing can bring embraced by health and social care, just as they've seen them in other parts of their lives.

The NHS and social care are poised to transform care for each of us from birth to the end of life, and using information and technology better is central to these changes. Deciding what information should be shared between the NHS, social care and people who use services and how it can be shared safely is fundamental.

The PRSB was commissioned by NHS England to define the information that should be shared, called a 'core information standard', by consulting widely with people who use services, health and care professionals. As a UK-wide body, PRSB consulted on the standard across the four nations, because people's health and care is provided across geographical boundaries and the information needed to provide safe, high quality care should follow the person.

The standard defines a set of information that may be shared between systems in different sites and settings, and with professionals and people using services. What information is accessed will differ depending on who is accessing it, for what reason and the wishes of the person the information is about. Its use will be decided locally; the Local Health and Care Record (LHCR) localities, under NHS England's LHCR programme, will set plans to adopt it early. After that, the standard will be rolled out nationally and can be used across the UK.

The project was carried out in two phases: the first phase reviewed evidence from existing standards and shared care records in order to produce a draft core information standard. The second phase of work developed the standard in key areas where it was seen that further work was needed (e.g. mental health and social care). The PRSB carried out broad and deep consultation and engagement across health and social care using online workshops, a national deliberative workshop, social media (to obtain more diverse input from the public), expert reviews, an online workshop for vendors and an online survey. This allowed the content of the information standard to be refined and started to build awareness and support among all the key groups with an interest in information sharing in health and care. The core information standard (Appendix B) is being formally endorsed by royal colleges and professional bodies and incorporated locally by vendors and LHCRs in their systems; at a national level incentives will also encourage wider adoption.

Defining a core information standard for use in shared care records is complex, important and challenging work, not only because of the scale of the information it contains but also because of the effects it might have when used. Though there was strong support for the benefits that sharing a wide range of care information would bring, there were also a wide range of views and concerns raised by professionals and users of services alike. The report details the issues raised during the consultation and makes recommendations which should form essential reading for any organisations creating shared care records. These include: implementation and usability, information governance and safeguarding, ownership and control of data, data quality and accuracy, professional best practice and training, the effect on person-centred care, and addressing potential barriers to sharing information between health and social care.

The findings are as follows:

- There is strong support for shared care records which are seen as improving accessibility, transparency and the relationship between professionals and users of services; people believe they will drive up the quality and safety of care and support self-management. But there is also confusion about how shared care information will work in practice; people who use services doubted they would be able to influence and control use of their data and professionals were concerned about information overload and usability. Some professionals also expressed concern about having access to less information through the loss of valuable existing systems as they are replaced by local shared care records.
- Many people told us that using the core information standard will be challenging given the huge variation in the uses for the information it contains. They said that this should not be treated as just a technical exercise but needs to address how people want to use the information in the future. Designing systems with users so that information is usable, accessible and relevant is vital, people told us. Concerns were raised about data quality and keeping timely and accurate information in such a complex, information-rich world. People said there is a need to be clear about what is good professional practice in recording information, for example diagnoses and problems, and they should make sure that the meaning of data isn't lost or changed when information is extracted from clinical records and shared. Training was said to be essential so that every system user is familiar with how to access, retrieve and use the data.
- Everyone strongly supported a person-centred approach to care and agreed that the 'About Me' information is critical to good care. People believe that better information sharing using the standard and shared care records could lead to a major change in the way professionals and people using services work together. However, there were also concerns raised about ownership and control of the information in care records. People said the 'About me' section lets them contribute important information about themselves. They also said they wanted to be able to comment on or edit information in their record and they wanted to be sure that the information they enter is acted on to improve their quality of life and their own ability to care for themselves. People said that data from mobile devices like Fitbits and mobile apps should be shared as it will also play an important part in people looking after themselves better and watching for signs of illness. Professionals questioned who would check and act on this data and they raised safety concerns should data be missed and not acted on; they also questioned how they would know whether the data is correct.
- People told us they want to be sure that their health and social care information will be held safely, that they will be asked to consent to sharing their information and that it will only be viewed when it is necessary for care. They want to know that audits will be in place to check who has viewed their information and any breaches will be reported to them promptly.
- People said that social care information involves a wide range of professionals and settings and that the culture and language differ from healthcare, which can create barriers to sharing. For example, social care is moving away from using computer-readable information towards more descriptive information about the person, whereas

healthcare is moving toward using more computer-readable information. This will make sharing more complex and possibly difficult.

- People said it was helpful that the core information standard draws on existing standards and system suppliers have already used many of its parts. However, people also said areas were missing from the core information standard that should be looked into further investigation, for example community, dental, optometry, screening, self-reported data and genetic data.

The PRSB has made the following important recommendations in six key areas as follows:

- A strong narrative that tells professionals and the public about the important gains to be made from sharing care information is needed. This should support a unified national programme of consultation and engagement to build understanding and win trust in how shared care records will be used in future. This is key if clinical, professional and public engagement in shared care records is to deliver benefits.
- Use of the core information standard needs national and local actions and must involve the professionals using the information, people who use services and system suppliers. At a national level, this could include using levers and incentives such as issuing an Information Standards Notice (ISN) or working with regulators to include the standard in their regulation of health and care. At a local level, each LHCR localities should work with vendors to test different uses of the core information standard to address any barriers to its use. The right professionals should be involved in the testing to ensure that systems provide the information they need in a way that is most useful. Where technical standards are needed to support sharing information, clinicians and professionals should be involved to make sure that they work for the user and are consistent with the PRSB information model. Further work should be commissioned to clearly describe good clinical practice in recording diagnoses and problems.
- More work is needed to understand what further information, not currently included in the core information standard, people want to share with professionals, for example health data from mobile devices, and how it could be used to improve health and care. Further work is also needed to better understand the benefits and effects of people accessing and contributing far more information to their health and care records, including more work on the 'About me' section, as information is more widely shared. The policy, strategy and safety issues that might arise from this should be addressed nationally so that local differences can be avoided. This should include work with NHS England's Personalised Care team and a LHCR to pilot use of a personal health record and measure its impact on users and professionals in line with local uses based on real-life scenarios.
- The core information standard should be reviewed in relation to NHS England's Information Governance Framework, once complete. A narrative is needed that describes how the Information Governance Framework will work in a way that can be

understood by professionals and the public. The framework should be tested in practice by the LHCRs, along with the core information standard, so that we can identify and resolve any barriers and prove that it works.

- A clear plan should be developed that sets out further engagement and consultation with social care professionals and service users across adult and children's social services and care providers to make sure that the shared information that is needed by social care professionals form part of the core information standard. This should build on existing links with the Local Government Association, NHS Digital Social Care programme and The Society for Information Technology Management (SOCITM).
- Work should be commissioned to develop the core information standard further in areas where there are gaps. Also, a UK-wide metadata standard (a standard about data itself) for documents and images should be agreed and applied to the core information standard. PRSB should review existing standards and align these to the new core information standard.

The core information standard that we have defined here is a reference framework for driving integrated care. Its development was prompted by the Local Health and Care Record programme but it is a major asset for digital information sharing generally. The core information standard is the product of collective efforts of clinicians, professionals, vendors and people who use services. The proof of its usefulness and usability will come through trialling it in practice, refining it and overcoming barriers so it can be adopted widely for the benefit of professionals and the people they serve.

## 2 Background

### 2.1 Introduction

The changes planned in health and social care over the next decade – from reducing premature births to helping people live healthier, longer and more independent lives – are all underpinned by better use of information and technology to improve care.

In order to realise these benefits, we need to agree what information should be shared and deploy systems that will talk to one another across health and social care, with the right safeguards in place.

There are currently in excess of sixty local shared care records in operation across the country. NHS England has established a programme, the Local Health and Care Records (LHCR) programme, to expand the coverage of local shared care records to cover larger populations. This will make important information available to health and care professionals and people using services across wider geographic areas, covering populations of three to five million, to improve the quality of care and care co-ordination.

The information will be brought together for individuals across the health and care settings in selected geographic areas, known as localities, to support integrated pathways of care, in the form of shared care records. The records will be accessible to people who use services, and authorised professionals and carers who need to see the record to provide care. They will not include all information about the person and will not remove the professional responsibility to verify the information with the person.

Although the primary focus of shared care records is to support direct care, a secondary objective is to be able to utilise de-personalised information in support of population health analysis and research. Collecting data covering populations of three to five million will enable significant analytic and research opportunities. Despite the shared care records covering large geographic and population sizes, movement of patients and citizens across boundaries will still take place and information will need to be shared across boundaries to support their care. Sharing information between organisations and across geographic boundaries requires that the information can be captured and shared in a standardised way and that the meaning and context of the information is maintained as it is shared. Sharing the information in a standardised way requires the development and use of information and technical standards.

NHS England set out initial expectations for the type of information that should be part of a core set of information (Appendix A datasets) and commissioned the Professional Record Standards Body (PRSB) to test this and seek consensus on what information should be shared. The PRSB is working with citizens and health and care professionals to define this in an initial 'core information standard'.

It is imperative that the core information standard has local buy-in and based on local needs, but with national consensus. To achieve local ownership and national consensus, a rigorous consultation approach involving national multi-disciplinary engagement and local engagement through local networks was key.

This work has resulted in a national core information standard to support sharing of information within and between LHCR localities based on the initial agreed scope, namely that of direct,

individual care. It is now expected that the technical specifications will be developed and localities will be expected to establish a plan to migrate towards the agreed standard.

## 2.2 The Core Information Standard

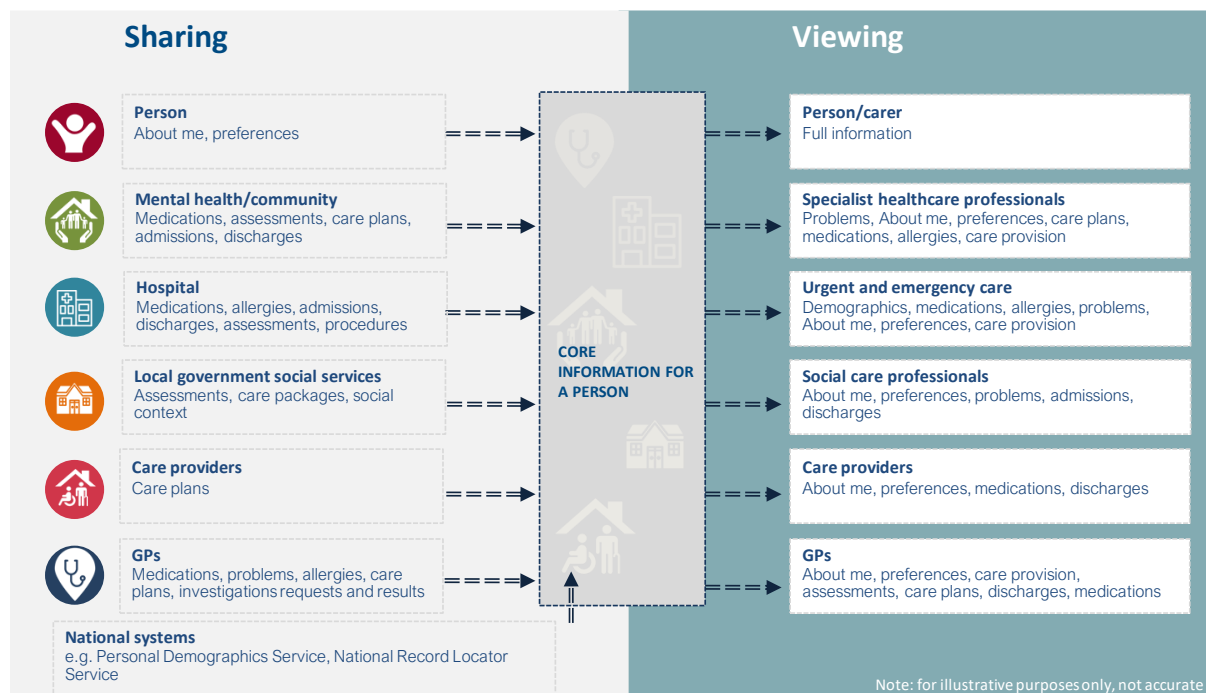
### How much information should be shared?

In the future, digital advances mean that most, if not all, information related to a person's health and care can be shared with care professionals and citizens themselves. This is subject to being able to demonstrate that there is a legal, justifiable need to share for the benefit of the individual.

We are some way from this goal today so we need to start with a modest set of core information that is a realistic and achievable goal for most health and care systems over the next few years. The core information standard will include important information from a range of sources including primary, secondary and specialist care as well as social care and information contributed by individuals themselves.

In consultation with professionals and citizens on what a standardised set of core information should include, it is clear that achieving wide scale adoption over time of even a modest set of information that can be shared between information systems would deliver profound improvements in the quality, safety and efficiency of care.

### The core information standard



The diagram above shows examples of information that may be sourced from different settings and the different views of the information that may be required for different professionals in different roles.

The core information standard defines a set of information that can **potentially** be shared between systems in different sites and settings, among professionals and people using

services. Which components of core information are accessed and used will be different depending on:

- Who you are, e.g. an A&E consultant, a GP, a physiotherapist, a person accessing their own records.
- The situation, e.g. a crisis or emergency situation, being discharged from hospital to a care home, managing a long-term condition.
- The wishes of the person the information concerns regarding who should have access to their information, e.g. an individual may object to their information being shared.

How these different views of information are physically presented in systems will be dependent on system vendors and local implementers. It should ensure that the required information is presented in a way that is useful and usable and supports professionals to do their work efficiently and safely and citizens to access the information they need to manage their own care.

The core information standard will provide a framework which local health and care systems can reference and move towards over time, according to their local priorities and capability to innovate and change at a speed that makes sense for them, and recognising the maturity of local source systems and their ability to interoperate. The core information is a baseline, and it is expected to evolve and grow as we learn from its practical application and use.

## **2.3 Project governance**

The national LHCR Programme has a specific work stream dealing with health and care professional engagement.

That work stream, overseen by the LHCR Health and Care Professional Group (HCPG) was originally chaired by the NHS England National Medical Director. At the time of writing this is transitioning to Dr Simon Eccles, the NHS Chief Clinical Information Officer. The work stream has established several projects including this one to define the core information standard. This project was commissioned by NHS England on behalf of the HCPG.

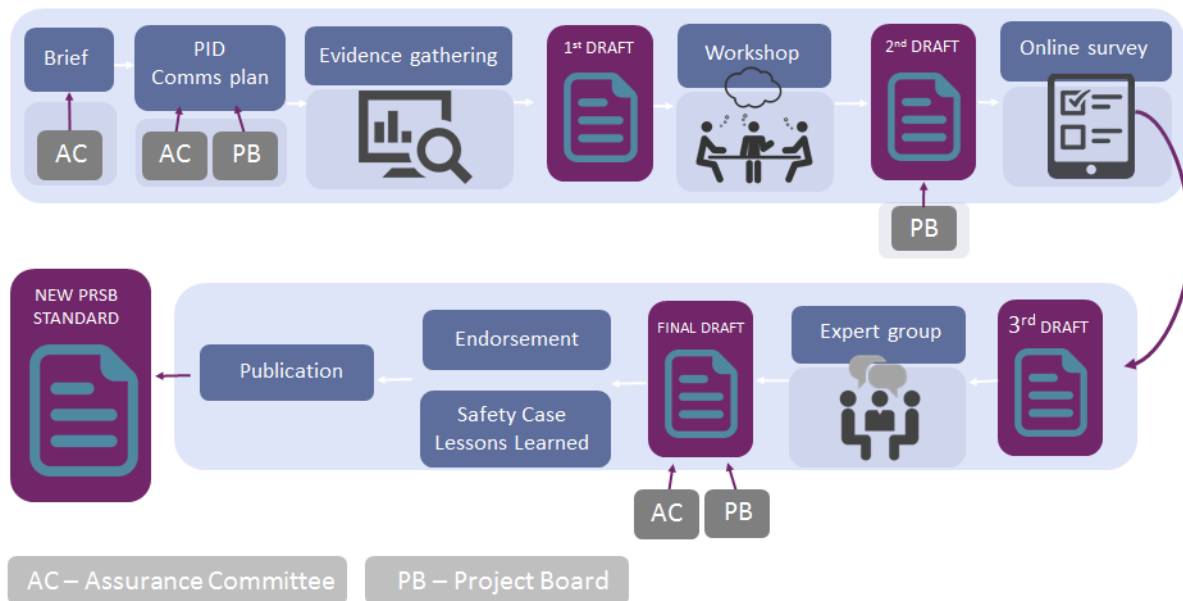
This project was led on behalf of the LHCR HCPG by the Greater Manchester LHCR clinical lead, Dr Gareth Thomas, who is also the Senior Responsible Owner of the national interoperability programme.

The core information standard had its own project board. Throughout the course of the project, John Farenden, NHS England, represented the project at the national LHCR programme board.

## **3 Approach**

### **3.1 Overall approach**

The project was conducted according to the PRSB process and assurance criteria.



The approach was undertaken in two phases:

- a **discovery phase (September 2018 – January 2019)** to identify the information requirements for sharing and where information standards already exist to support this.
- **phase 2 (January 2019 – May 2019)** to develop the information standards in key areas identified during the discovery phase as requiring further work, e.g. mental health and social care. We also mobilised multi-disciplinary consultation and engagement to further refine the content of the information standard build awareness and support across all key stakeholder groups. This has resulted in a core information standard (Appendix B) for which formal endorsement will be sought from the royal colleges and professional bodies. This product will enable technical specifications to be developed and LHCR localities to move forward on their plans for aligning with the standard. It will also provide a basis for aligning system levers and incentives to encourage the adoption of the standard (for example by inclusion in the Health and Systems Support Framework (HSSF)). The scope of the core information standard is for direct / individual care. The content of the standard is expected to evolve over time as it is trialled and put into practice and new requirements are identified.

### 3.2 Discovery Phase

The objectives of the discovery phase were to:

- obtain agreement on the use cases for sharing information between LHCR localities (this was restricted to the first wave of agreed localities – five areas)
- jointly, with the first wave LHCR localities, define and obtain consensus on a definition of a draft core information standard; a minimum set of information needed to ensure care co-ordination and the continuity of care based on a set of use cases
- develop and agree recommendations for future phases of work to fill the gaps in the core information standard and to potentially extend the core.



The draft core information standard was developed by mapping NHS England's definition of the core information set (Appendix A), the Greater Manchester core dataset (Appendix C<sup>1</sup>) and the PRSB Standards for the Structure and Content of Health and Care Records (Appendix C<sup>2</sup>) (PRSB standards) against the national and international standards and records (Appendix C<sup>3-10</sup>).

The starting point for the core information standard was the existing section or sections from the PRSB standards that corresponded to the information requirements identified from the mapping. This was because the elements within each section have already been extensively consulted on as part of the PRSB standards development process and some also have corresponding technical messaging standards to enable interoperable sharing of the information. Where there was no corresponding section from the PRSB standards the identified as requiring further work.

Representatives from the LHCR localities and experts/clinical leads were consulted to validate assumptions about the information components that should be part of the core information standard leading to strong consensus on seven key topic areas for further work (a list of the consultees can be found in Appendix D).

The following areas were proposed for further work as part of the LHCR programme:

- Input from people who use services and their carers
- Social care, including both sharing with local authorities and care providers.
- Parts of the maternity and healthy child records that should form part of the core information standard
- Requirements to share encounters, alerts, test orders and future appointments
- Requirements to share mental health information
- Confirmation that requirements for end of life care is supported
- Confirmation that the requirement to link to a genetic report is supported

### **3.3 Phase 2**

The objectives of Phase 2 were:

- To test and validate the definition of the core information standard and the principles which should guide its use.
- To strengthen the core information standard content by undertaking sufficient research, analysis and consultation with experts in the areas identified as requiring further work to enable full and meaningful multi-disciplinary and citizen consultation on the full standard.
- To consult and engage on the full standard and its use with the LHCR localities and a broad multi-disciplinary range of professional and other stakeholders, patients/public and their advocates.

- Test the first draft of the standard and the information to be included with consultees and capture any suggested changes, additions or improvements
- Capture any implications, considerations or concerns regarding how the core information standard could affect how care is provided or received from the perspective of:
  - People (citizens, patients, carers)
  - Health and social care professionals
- Help consultees to think about how care could be delivered and not be limited by current models of care provision
- To update PRSB information models to accommodate the standard; and to develop associated non-technical implementation guidance to support adoption.
- To develop a clinical safety report and associated hazard log.
- To gain endorsement from relevant professional bodies for the core information standard.
- To raise awareness and build understanding of what the core information standard is and how it could be used and build support for the proposed changes.

A project team was established which included professional and patient advisors (see Appendix E).

The core information standard was enhanced through research and development of those areas identified in the discovery phase as requiring further analysis. Comprehensive consultation with all stakeholders was then undertaken to develop this current release of the standard. The consultation approach is described in more detail in the following sections.

## 4 Consultation and Engagement

### 4.1 Objectives

The objectives of the consultation were as follows:

- Raise awareness and build understanding of what the core information standard is and how it will be used.
- Consult with subject experts and others to develop the immature areas of the draft standard to produce a more rounded version.
- Consult widely and test the draft standard with a broad range of multi-disciplinary professionals and citizens and incorporate their feedback.
- Capture any implications, considerations or concerns regarding how the core information standard could affect how care is provided or received from the perspective of:
  - People (citizens, patients, carers)

- Health and care professionals
- Help consultees to think about how care could be delivered and not be limited by current models of care provision.
- Produce a version of the standard that is fit for purpose and has broad buy-in and support from the professions and people that will use it.

## 4.2 Scope of consultation

Included in scope:

- Development of the core information standard including the less developed areas and gaps identified in the initial phase of work.
- Consultation on the complete content of the standard and any implications, considerations and concerns relating to its use.
- Organisations and individuals representing people who will use the standard.
- Representatives of all the disciplines of health and care who may use or contribute to the information shared using the standard.

Exclusions from scope:

- The consultation excluded any detailed consideration use of the standard for sharing information for population health management and research purposes other than having prepared answers for the questions likely to arise in consultation regarding wider use of the data.
- The consultation excluded considerations of the information governance and data sharing considerations relating to the core information standard other than having prepared answers for the questions likely to arise.

## 4.3 Key themes of the consultation

The consultation addressed the following key themes and risks that had arisen during the discovery phase.

- There was considerable confusion about what the core information standard is and how it would be used even amongst informed groups. In conjunction with NHS England, PRSB defined the core information standard with a set of frequently asked questions for use during the consultation process and tested that this was understood.
- The ambition is that in future, people will take far more responsibility for their own care, and this will require confidence and competence in accessing their own records. Significant weight was given to what people want to see in the information standard and input from people and their advocates must be given high priority in the consultation. In particular, the consultation prioritised representation of those who are likely to be the heaviest users of the information, e.g. those with long term conditions.
- The consultation was very broad and wide ranging and the uses of the core information standard far more complex and varied than more typical PRSB standards consultations. The single workshop provided insight but the limitations should be

appreciated. An ongoing campaign of engagement and consultation is likely to be required over a period of years.

- The core information standard is a national standard and not just for the LHCR localities. Consultation participants were drawn from across PRSB membership as well as representatives from the LHCR localities.
- A discussion about the technical implementation of the standard risked monopolising the debate rather than focusing on the content. Statements were drawn up to differentiate between the core information standard content and how it should be implemented locally.
- There is high sensitivity regarding how personal data will be used for purposes other than direct care and also what information will be shared with which professionals. There was a risk that this could skew responses to consultation if not proactively addressed. A narrative was developed with NHS England to clarify how data will be used for purposes wider than direct care and how information governance policies will be developed and implemented to provide reassurance regarding its use.
- During the discovery phase clinical engagement with the LHCR localities was limited. Agreeing the vision and the core information standard is a critical part of local engagement and buy-in and vital to successful implementation. LHCR clinical leads and other team members were invited to all consultation events and localities were encouraged to use a tailored version of the national materials to undertake comprehensive local engagement supported by the PRSB team. However, this offer was not taken up. The PRSB therefore took the opportunity to engage with the local teams where possible, for example we were closely with the OneLondon LHCR locality on the information modelling and with LHCR systems suppliers who provided valuable input.
- Vendor compliance with the standard will be key to its successful uptake. This version of the standard will be incorporated in the HSSF when the technical specifications have been developed. The national workshop had limited places and prioritised professionals and service users. Tech UK was included in the workshop but an additional supplier webinar was organised to start engagement with suppliers. On-going engagement with suppliers will be key.
- The programme has established parallel work streams to engage councils in the wider LHCR programme. This includes establishment, by the Local Government Association, of a local authority network and engagement programme. The Society for Information Technology Management (SOCITM) engaged with local authorities and we worked with SOCITM to gather input from councils to help inform the core information standard.

#### **4.4 Participant framework**

The stakeholders identified for this project are set out in Appendix F. This was used to develop the participant framework which sets out the individuals who represent these stakeholders and their involvement in the consultation. This spreadsheet is not ordinarily distributed because it contains personal information, but the analysis enables the project to answer specific questions on who from each stakeholder organisation participated in each consultation event.

## 4.5 Consultation methods and approaches

The following methods were adopted:

### Consultation on areas requiring further development and analysis

- Evidence review, research and analysis of topic areas of the information standard identified as needing further work.
- Interviews with subject matter experts.
- Citizen focus group for people who use services and their carers.
- Webinars to draw together findings and build consensus with the topic specialists and a general audience.
- Social care topic included consultation with local authorities via SOCITM and engagement with the Care Provider Support Service network.

The particular themes and consultation questions tested in the focus group and webinars can be found in Appendix G.

The webinars held were as follows:

Topic	Date	Invitees
People using services and their carers	27/02/19	People who use services and their carers, clinicians and professionals
Social care	26/02/19	Social workers, carers, patients, health visitors and care home professionals.
Encounters, alerts, appointments and test orders	20/02/19	Technical architects, informaticians, clinicians and people who use services
Maternity and healthy child	26/02/19	Pregnant women, parents, midwives, obstetricians, gynaecologists, surgeons, paediatricians, paediatric nurses, genomics experts, social workers, health visitors, dieticians, dentists and other professionals from across health and social care.
End of life	19/02/19	Clinicians, palliative care nurses, carers, hospice professionals and other end of life care specialists
Mental health	26/02/19	Mental health professionals, carers and patients.

Webinar recordings are [available here](#).

Lists of attendees for these events can be found at Appendix H.


### National consultation workshop

The output of the work on the topic areas identified above was consolidated within a next iteration of the core information standard and reviewed with professional and patient project leads leading to a version for consultation at the workshop.

A national all-day workshop was held to test the draft standard and to address the consultation objectives and consider the content of the standard, implementation considerations and risks.

The workshop included 70 participants with representation from the LHCR localities and a cross-section of clinical disciplines, social care, patients, carers and service user representative groups who valued the discussion, and different perspectives shared.

Feedback from the workshop was extremely positive with most rating it 4/5 or 5/5.



*“It was really good to hear the different perspectives and the tables were well balanced. Case studies were challenging and represented real world complexity.”*

Output from the workshop was discussed with the project advisors and the models updated informed by their review. This model was also shared with the NHS Digital terminology team to identify any SNOMED CT messaging requirements and reference subsets Discussion have been held with the terminologists and the value sets updated.

The particular themes and consultation questions tested in the focus group and webinars can be found in Appendix I.

A list of attendees can be found in Appendix J.

### **Online survey consultation**

Building on the findings from the consultation webinars and workshops and the consultation objectives and themes, a survey was designed using Survey Monkey to reach the widest possible number of frontline professionals and patients, carers and service users or their representatives.

The survey and accompanying consultation document were hosted on the Professional Record Standards Body (PRSB) website and the Clinical and Professional Advisory Group (CPAG), and promoted via the Royal College of Physicians, PRSB and partner organisations’ social media channels.

The survey was sent to 1325 individuals, including PRSB advisory board representatives, patient and carer groups, royal colleges, specialist societies and other professional bodies in health and social care to distribute across their networks. Additionally, it was distributed to PRSB’s 708 newsletter subscribers, the 413 stakeholders who we identified as possible attendees for the webinars and workshops, and past workshop attendees. The survey was featured in a number of publications such as the NHS Improvement provider bulletin, Digital Health Intelligence, NHS England CCG bulletin, NHSE Informed and NHSE Intouch, on professional platforms such as Ryver and with groups such as the Pharmacy Digital Forum and Scottish Children’s Cancer and Leukaemia Group members.

The survey was also publicised through the chief social and adult and children’s social care directors, the care provider alliance representing up to 2 million working in domiciliary care and care homes, system suppliers, LHCR teams and patient groups such as the Wellcome

Trust, Understanding Patient Data, National Voices (representing 140 charities) and the Patient Information Forum (representing 300+ charities).

The survey ran from 1 April 2019 to 1 May 2019, with 1010 individuals participating. The survey responses were collated and analysed (both quantitatively and qualitatively) and have been used to inform the recommendations for this report. The survey report can be found [here](#).

The survey design can be found at Appendix K.

### **Requirements Log**

A requirements log was maintained to capture requirements identified from sources outside of the main consultation process (e.g. email). This, together with the webinar and workshop outputs were analysed to synthesise themes which emerged from consultation and identify new requirements.

### **Expert reviews**

Following the consultation, the core information standard was reviewed by an expert group of informaticians and project advisors with a particular focus on resolving outstanding issues with the information model. There were two expert group review meetings, on 1 and 16 May 2019. Expert group participants are listed in Appendix L. The questions asked at the expert group meetings are included in Appendix M. Outputs from these meetings were fed directly into the information model and into the implementation guidance where necessary.

### **Supplier Webinar**

Suppliers listed on the Health and Systems Support Framework were invited to a webinar on 8 May 2019 to discuss the core information standard and provide their views on the design, in particular in the context of any existing health and social care products which they offered, and future interoperability. The consultation questions are set out in Appendix N.

Outputs from this webinar have been used to inform the recommendations in this report.

Attendees at the supplier workshop can be found in Appendix O.

## 5 Core Information Standard - information model

The information model is included in Appendix B and can also be found [here](#).

## 6 Implementation guidance

The implementation guidance was developed through the consultation process and expert group discussions to provide additional information to use of the standard in practice.

PRSB standards include implementation guidance intended for the following audiences:

1. Technical messaging specification developers
2. System suppliers incorporating the standards into systems and implementation teams at provider organisations
3. Users of standards in their roles as health and care professionals, patients, carers and citizens

The implementation guidance can be found [here](#).

## 7 Clinical safety case and hazard log

The PRSB is producing a clinical safety case and hazard log. The approach follows the standard approach to clinical safety for the NHS and complies with DCB 0129 (for IT suppliers). Further information can be found at <https://digital.nhs.uk/services/solution-assurance/the-clinical-safety-team/clinical-risk-management-standards>

The approach that will be taken is:

1. Identify risks and hazards from the consultation outputs:
  - Hazard workshop
  - Workshop and webinar outputs
  - Clinical and other expert reviewer meetings
  - Survey consultation findings
  - Review hazards from other relevant PRSB standards
2. Develop hazard log
3. Develop clinical safety case from hazard log
4. Assure and approve hazards log and clinical safety case
  - Seek NHS Digital clinical safety team approval
  - Seek PRSB Assurance Committee approval



- Clinical safety officer hands over clinical safety care to PRSB clinical director (owner)
5. Hand over ownership of clinical safety case and residual risks to NHS Digital.

The core information standard clinical safety case will be published shortly.

## **8 Endorsement**

Formal endorsement, of the standard will be sought from a wide range of organisations. Not all organisations are able to formally endorse and where the support of an organisation is deemed essential but the organisation is not able to endorse, the PRSB will seek a statement of support for the standard. PRSB will ask the following organisations to formally endorse or support the standard:

- Academy of Medical Royal Colleges
- Association of Directors of Adult Social Services
- Association of Directors of Children's Social Services
- Care Provider Alliance
- National Voices
- Patient Information Forum
- Royal College of Emergency Medicine
- Royal College of General Practitioners
- Royal College of Nursing
- Royal College of Paediatrics and Child Health
- Royal College of Physicians
- Royal College of Psychiatrists
- Royal College of Surgeons
- Tech UK

## 9 Findings and Recommendations

A summary of the recommendations can be found in the table below:

<b>Recommendations</b>	
<b>Professional and public engagement</b>	
1	Deliver a joined-up national programme of engagement with the public and health and care professionals covering the core information standard and how it will be used, information governance and implementation. This programme should develop a strong narrative about the important gains to be made from using shared information. The programme should draw on findings from this initial consultation work and support from PRSB's member organisations as well as other national bodies to deliver clear and consistent messages through trusted channels.
<b>Implementation</b>	
2	System levers and incentives should be considered. This could include issuing an Information Standards Notice (ISN) or working with regulators to incorporate the standard into their assessment regimes
3	LHCR localities should trial the core information standard alongside the Information Governance Framework. This will enable better understanding of the challenges of implementation, identify the need for refinement of the core information standard and enable the evaluation of the impact on ways of working to support a national rollout.
4	Address the concerns about information overload through work to identify what information different end user groups need to see in different situations. Working with key professional groups (e.g. A&E consultants) and vendors to develop a series of best-practise examples for key use cases will greatly enhance understanding and can also be used as a model for live implementation as required.
5	The development of a logical data model and technical messaging specifications (FHIR profiles) should be commissioned to enable the technical implementation of the standard. Clinical and professional input is required to ensure that the core information standard is correctly reflected in these technical specifications including addressing the clinical context concerns.

6	A further stage of the problem and diagnosis recording work should be commissioned to address the representation of diagnoses and the curation of problem lists.
7	Undertake a thorough assessment of the content of the Summary Care Record, and any other interfaces or records that may be retired as a result of the migration to local health and care records, against the core information standard to ensure no content is not lost as a result of the migration.
<b>Person-centred record</b>	
8	More work is needed to understand what other information, not currently included in the core information standard, people want to share with professionals, for example health data from mobile devices, and how it could be used to improve care. Further work is also needed to better understand the benefits and effects of people accessing and contributing far more to their health and care records, including more work on the 'About me' section, as information is more widely shared. The policy, strategy and safety issues that might arise from this should be addressed nationally so that local differences can be avoided. This should include work with NHS England's Personalised Care team and a LHCR to pilot use of a personal health record and measure its impact on users and professionals in line with local uses based on real-life scenarios.
<b>Information governance</b>	
9	Align the core information standard with the Information Governance Framework when the work has concluded.
10	Develop a narrative that describes how the Information Governance Framework will operate in a way that is accessible and understandable to professionals and the public. The framework should be tested in practice by the LHCR localities, alongside the core information standard, to identify and resolve barriers and prove that it works.
<b>Information sharing between health and social care</b>	
11	Develop a plan that sets out further engagement and consultation with social care professionals and service users across adult and children's social services and care providers to ensure that the shared information requirements of social care professionals are reflected in the core information standard. This should build on existing links with the Local Government Association, NHS Digital Social Care programme and The Society for Information Technology Management (SOCITM).

Development of the core information standard	
12	Develop a consensus-based metadata standard for documents and images for use across the four nations that can then be applied to the core information standard.
13	Scope a future programme of work, investigating the inclusion of the information content identified in the consultation as missing from the current version of the core information standard. Feedback should also be obtained from trialling the standard and incorporated into any future work programme.
14	PRSB should review existing standards in light of the development of the core information standard to align existing standards with this standard.

## 9.1 Professional and public engagement

Whilst there is a groundswell of opinion that moving towards integrated care records will provide opportunities to improve quality and safety and help support people who access services to have more control and manage their own care, as evidenced in our survey findings, people are also understandably wary about how it would work in practice.

We found considerable confusion and differing assumptions about what the core information standard is and how it will be used. It has proved difficult to socialise the concept of a core information standard as it is different to more straightforward standards with a simple, narrowly defined set of use cases, and people lack a frame of reference and examples of how it could work.

Although there are more than 60 shared care records already in operation across the country at different levels of maturity, the potential to share all the information outlined in the core information standard represents a step change. First the information would be shared across larger geographic areas and on demand across a far wider range of organisations, and professionals. In addition, information would be accessible to people using services and in future they will be able to contribute to their record and by extension care and treatment.

This has the potential to create far more joined-up care that is safer and better and also put people in far more control of their own care.

The transparency that this implies will be far-reaching in its implications and consequences. It will also require that users think and act differently in relation to what information needs to be shared, how it is shared and used to discuss and plan care with colleagues and most importantly people who use services.

There will be a need to re-imagine how services work in light of these advances, with a move towards increased partnership working between citizens and the professionals with whom they interact, and in how service users interact with the technology.


Whilst there is undoubted support for the concept of shared care information, we encountered significant cynicism regarding what would be different this time, in particular how the needs of the 'users' (health and care professionals and users of services) would have primacy in driving solutions that meet their needs. Health and care professionals expressed concerns about information overload, ease of access to important and relevant information in time-pressured clinical settings, and their responsibilities in relation to the information (in particular information entered by citizens). There was also concern about how the implementation of the standard would affect highly-valued existing systems and services, for example pharmacists were concerned about the on-going availability of the Summary Care Record and although a policy statement has been issued on this we found limited awareness of this. Citizens expressed concerns about information being shared inappropriately, e.g. with commercial organisations, without their consent, the security of systems and ability to access their information.

Whilst the primary driver for this work was the national LHCR programme, we found substantial interest and engagement from non-LHCRs and strong interest from Scotland and Wales in adopting the standard.

There is a need to build understanding and trust in shared records. This includes how the records will be implemented (the roadmap), the plans for the Summary Care Record, how the information will be used, who it will be shared with, how it will be accessed and how it will be secured. Without this investment in the user perspective alongside delivering the technology, the programme is unlikely to succeed or deliver the benefits to quality and safety of care that are within grasp.

## **Recommendation**

1. Deliver a joined-up national programme of engagement with the public and health and care professionals covering the core information standard and how it will be used, information governance and implementation. This programme should develop a strong narrative about the important gains to be made from using shared information. The programme should draw on findings from this initial consultation work and support from PRSB's member organisations as well as other national bodies to deliver clear and consistent messages through trusted channels.



*"There has seemingly been no consultation about national concerns and no-one leading this to engage the public"*

PRSB Survey April 2019

## 9.2 Implementation

There was clear recognition that whilst successful implementation of the technology is essential, it is not enough in isolation to enable achievement of the benefits and adequate consideration of the implications for care professionals in doing their jobs and citizens interacting with them is an essential pre-requisite to drive the required transformation.

Due to the nature of the core information standard and its varied application across a wide range of use cases, the diversity of users, systems and organisations from which the core information could be drawn and the different options for how implementation can be achieved, implementation is inherently very challenging. This will be driven by local use cases and priorities.

Implementation is not constrained within an organisation but will include local health and care systems and potentially interchange of information with any other LHCR localities or care systems anywhere in the country. Rates of implementation will vary with much work to be done to fully consider the implications of sharing information between partners with varying maturity and at different stages in progressing implementation of the core information standard.

A number of considerations for implementation were raised including avoiding information overload and presenting it in a way that it is easily accessible and relevant to the user. There is a risk that without good understanding and design, information is not presented in a way that enables information to be shared which is useful and safe. Concerns were raised, about information being presented differently in different localities, requiring training and familiarisation if moving between geographies.

Concerns were also raised about how data quality would be maintained and how it would be kept up-to-date and accurate. An example highlighted concern about data held on more than one underlying system being inconsistent e.g. blood pressure; emphasising the need for maintaining information about the provenance of the data.

The core information standard draws heavily on existing standards and technical messaging specifications (Fast Healthcare Interoperability Resources or FHIR profiles) exist for some, but not all, of the components. Where they exist, systems suppliers may already have implemented or plan to implement many of these standardised components, minimising the change needed to align to the core information standard. Where they do not exist, it is important that they are commissioned, so that systems suppliers can ensure compliance.

Traditionally, information has been shared between healthcare professionals in different care settings through correspondence such as referral letters, discharge summaries and outpatient letters. A discharge summary may contain a list of diagnoses that were made following investigations or examinations and a list of medications that were prescribed during a stay in hospital. The core information standard changes the way this information is shared. It extracts diagnoses and medications from the discharge summary and puts them alongside other diagnoses or medications prescribed, for example, by a GP or in another setting. It is very important for professionals to be able to understand the clinical context in which a diagnosis was made or a medication prescribed and this was raised as a clinical safety risk as part of the consultation. The principle that no contextual information should be lost when sharing information should be adopted.

Although the core information standard requires that the professional that undertook the activity e.g. a prescription or an examination (along with some additional information about where and when the activity was performed) and the person that recorded that the activity has taken place should be recorded, it does not describe the potential links between the information (for example the link between investigation results and diagnoses or discharge summary and medications). The information model does not contain all the possible links between information and, therefore, the context should be described in the logical data model and FHIR profiles.

The difference in the recording of problems and diagnoses between primary and secondary care was discussed in the consultation. The Royal College of Physicians in conjunction with the PRSB is nearing completion of a piece of work to improve recording of problems and diagnoses (getting consensus on good professional practice). The issue of problem list curation and the need to manually maintain records was discussed by the expert group and it was recognised that further work was needed, taking into account the requirements for systems, and developing a knowledge base on how best to represent different conditions (e.g. a serious diagnosis such as diabetes is always considered 'active'), so that the underlying problem/diagnosis facts can be viewed in a clinically useful way without too much manual effort of problem list curation.

People raised the need for adequate time to be planned into local implementation schedules for training and familiarisation; this is likely to not only be about systems implementation but about re-engineering processes and the deep cultural and mind set shifts required to current behaviours and work practices.

## **Recommendations**

2. System levers and incentives should be considered to support adoption. This could include issuing an Information Standards Notice (ISN) or working with regulators to incorporate the standard into their assessment regimes.
3. LHCR localities should conduct robust trialling and testing the core information standard alongside the Information Governance Framework. This will enable better understanding of the challenges of implementation, identify the need for refinement of the core information standard and enable the evaluation of the impact on ways of working to support a national rollout.
4. Address the concerns about information overload through work to identify what information different end user groups need to see in different situations. Working with key professional groups (e.g. A&E consultants) and vendors to develop a series of best-practise examples for key use cases will greatly enhance understanding and can also be used as a model for live implementation as required.
5. The development of a logical data model and technical messaging specifications (FHIR profiles) to enable the technical implementation of the standard should be commissioned. Clinical and professional input is required to ensure that the core information standard is correctly reflected in these technical specifications including addressing the clinical context concerns.
6. A further stage of the problem and diagnosis recording work should be commissioned to address the representation of diagnoses and the curation of problem lists.

7. A thorough assessment should be undertaken of the content of the Summary Care Record, and any other interfaces or records that may be retired as a result of the migration to local health and care records, against the core information standard to ensure no content is not lost as a result of the migration.

### 9.3 Person-centred record

Implementing the core information standard will facilitate a paradigm shift in the relationship between the individual and the professional care provider. There is growing acknowledgement that health and social care is a partnership between individuals and the professionals who provide their care, and that the individuals should be as much at the centre of driving requirements as the professionals.

The implementation of the core information standard also offers people tangible opportunities to be more autonomous and take greater responsibility for their own health. This has been eloquently articulated by the individuals participating in consultation events, including people who use health services, social care and mental health services.

There is much interest in this work from people who use services and their carers and there was a clear message that their requirements are as important as requirements for professionals. For some people, the ability to record important information about themselves such as 'my religion means I do not want blood transfusions' or 'I am a carer for my disabled wife I need to know that if something happens to me that someone will contact her' or 'I can get very anxious because I suffer from dementia but the following things calm me down' in an 'About me' section can mean the difference between improved quality of life and supported self-management, or, if not known or ignored, poorer quality of life and dependency upon costly services. Over 80% of survey respondents said that an 'About me' section should be prioritised as part of the core information and of all the sections 'About me' along with medications and allergies were listed as the most important sections by GPs, secondary care doctors and people who use services. People also said that consideration should be given to providing more structure in the 'About me' section.

In consultation discussions, people also raised the availability of person-generated health data (which will rapidly increase over time with more apps and wearables) and the ability to upload this type of information into a record. This phase of work did not specifically include person-generated health data such as blood pressure and therefore, it is something that would require future investigation as to whether and how this type of information would be used in a shared information set to deliver benefits.

Over 50% of the survey respondents were concerned about people contributing to and sharing their information and could foresee issues with this. Concerns were raised in relation to data entered by individuals such as responsibility to review the information and potentially act upon it (raised by GPs), the additional burden of work on the professional, the accuracy and timeliness of the data entered. These would need to be addressed as part of future work.

People using services described how they wanted to access to information to be controlled and this is set out in section 9.4 below.

Concerns were also raised about inequality of access e.g. those not having access to a computer, the elderly, or those with learning difficulties.



Work to date has only scratched the surface of assessing the impact that information sharing, based on the core information standard, will have on citizens and much more needs to be done to understand the benefits and implications.

## Recommendations

8. More work is needed to understand what other information, not currently included in the core information standard, people want to share with professionals, for example health data from mobile devices, and how it could be used to improve care. Further work is also needed to better understand the effects of people accessing and contributing far more to their health and care records, including more work on the 'About me' section, as information is shared more widely. The policy, strategy and safety issues that might arise from this should be addressed nationally so that local differences can be avoided. This should include work with NHS England's Personalised Care team and a LHCR to pilot use of a personal health record and measure its impact on users and professionals in line with local uses based on real-life scenarios.

*"In my experience, the struggle to access my own health records dramatically increased the burden on me as a patient. It resulted in a needless wait of over 15 months for bowel cancer treatment. Throughout these long months I felt powerless, vulnerable, anxious... and very much lost in the system with no access to the information that might empower me to raise concerns and to take greater responsibility for my health.*

*I'd have loved to see referral letters and communication between providers, knowing where I was in the system, where I was headed, and how long I must wait. I needed a helping hand – information on who was responsible for which aspect of my health and how to contact them.*

*Yet what I have learnt from the NHS system is that the only person who can be ultimately responsible is the individual themselves and you cannot champion yourself without access to your own medical information. This is why strengthening public voice in record standard projects is so very important"*

Laura Fulcher, the patient lead for the project

## 9.4 Information governance

While people broadly welcome the greater accessibility of digital health and care information, they also rightly seek assurances that their information will be appropriately safeguarded, subject to their control, through robust consent-to-share processes, and audits that are transparent.

Information governance was not within the scope of this work, it is a separate work stream of the national LHCR programme, however it is clearly a major and contentious issue. At the time of writing, the national information governance framework (for sharing information for direct care) is being finalised and hence implications for the core information standard have not yet been fully assessed. Polarised views have been expressed regarding data ownership and access rights, including who owns the information, the model for consent, who has access to what information (would clinical safety override any access controls), what latitude is there for local variance in how the information governance framework is interpreted/implemented?

It is clear that people can only sensibly consider and evaluate the core information standard if they have a clear understanding of how information governance will be managed. There is a risk that people will not engage with the standard if they are not confident in the information governance, the two are inextricable.

A consistent theme among people who use services has been that information should be shared with professionals on a 'need to know' basis and that people should own and have access to all their information. During the consultation it was clear that some people using services would want access to information as soon as it becomes available, e.g. test results, to avoid the anxiety of waiting, however, others may not want this as interpretation of the results may be of concern. Another concern raised was could vulnerable people be coerced into allowing a third party to access their information e.g. an abusive partner?

A further persistent theme was consent. In healthcare, implied consent - a valuable asset - is predicated upon the patient's trust in the professionals providing their care and this works effectively and minimises burden. We found that introducing the concept of a core information standard and far wider sharing of information causes anxiety and an impulse to 'over-legislate' with some people suggesting that consent should be sought at multiple levels. Professionals and systems implementers expressed concerns about having to manage potentially complex and layered consent rules, whilst people using services lack confidence and trust in data security and the legitimacy of access in terms of a 'need to know' basis and commercial exploitation.

For care providers in social care, it was identified that there had historically been a lack of investment in information governance and there is variable digital maturity across the sector. However it is recognised that this is changing with the work of NHS Digital's social care programme which is helping care homes to achieve compliance with its Data Security and Protection Toolkit so that information can be shared.

### Recommendations

9. Align the core information standard with the Information Governance Framework when the work has concluded.

10. Develop a narrative that describes how the Information Governance Framework will operate in a way that is accessible and understandable to professionals and the public. The framework should be tested in practice by the LHCR localities, alongside the core information standard, to identify and resolve barriers and prove that it works.

## 9.5 Information sharing between health and social care

Social care covers a large number of professionals and settings including care home providers, domiciliary care providers and councils with different organisations being at different stages of digitisation and standardisation. The different cultures and even language used presents familiar but significant barriers to effective standards-based interoperability between health and care. For this reason, a particular focus was put on social care in the consultation. During the consultation we were told that, in social care, importance is placed on capturing information about the person in descriptive form. This is different from health care which is moving to a much more structured and coded way of capturing information.

Existing standards, including the digital care and support plan, used in the core information standard, such as the standard for digital care and support plans, have previously had input from social care professionals and consultation on the core information standard has also involved social workers and representatives from care homes. It should be noted that there was limited engagement with children's social services, an area that may require further future work.

Separately, work to explore standards use and barriers to standards adoption in councils was commissioned from the Society for Information Technology Management (SOCITM) by the Local Government Association working with NHS England. The draft SOCITM 'Local Government Social Care and Interoperability Standards Discovery Report' was issued for review and comment in April 2019. PRSB have worked closely and collaboratively with SOCITM and the Local Government Association to align our work including questions fielded to local authorities by SOCITM on our behalf regarding their needs of the core information standard. The report identified that:

*"Engagement with councils through this project has highlighted local areas where significant progress is being made to support the sharing of information across health and care (areas including Rotherham and Nottinghamshire).*

*However, the engagement has also highlighted several themes where councils and system vendors report challenges. There are a range of barriers that have been reported through this discovery from being able to effectively articulate and demonstrate the benefits of interoperability across social care to issues around information governance and data quality.*

*On the whole, further support to councils in the area of information sharing and standards adoption across care and health is welcomed. However, any approach will need to be multifaceted and start from practical use cases that speak to a social care audience for it to be successful.*

*Finally, although a standards-based approach was broadly supported by councils this discovery has demonstrated a preference for information sharing initiatives and activity which is local and collaborative rather than national and/or mandated."*

Whilst some localities are driving forward excellent work between health and social care, there remains a broad gulf that must be bridged in order to enable seamless provision of care for people and this is reflected in the requirements for sharing of information. The conversations are still in the early stages and there is much still to do. Development of the core information standard has provided a common platform to bring stakeholders together and this should be nurtured and developed.

## **Recommendation**

11. Develop a plan that sets out further engagement and consultation with social care professionals and service users across adult and children's social services and care providers to ensure that the shared information requirements of social care professionals are reflected in the core information standard. This should build on existing links with the Local Government Association, NHS Digital Social Care programme and The Society for Information Technology Management (SOCITM).

## **9.6 Evolution and further development of the core information standard**

The core information standard has been developed through extensive consultation, resulting in a first version which has broad support. This process has facilitated the identification of many issues and, where possible, the standard has tried to address or highlight them in this report. It is also recognised that this standard will develop and evolve as it becomes widely used.

The lack of a PRSB-assured information standard for correspondence (and documents or images) metadata was identified during the initial work mapping for the core information standard, in autumn 2018. It was assumed, at the time, that this would be commissioned and progressed separately. This has not happened and as correspondence, documents and images have been identified as key requirements of the core information standard, a decision was taken to develop a starter-for-ten set of metadata for the core information standard based on the approach being used by the OneLondon LHCR locality and incorporating the PRSB document naming standard. (This will support the transition from unstructured to structured data.) The issue is that there are different metadata approaches for documents already in use across the country and in order to develop a metadata standard acceptable across the four nations, a piece of work to gain consensus on a single national information standard is necessary.

The online survey asked what information was missing from the draft core information standard and although many respondents suggested that the standard was very comprehensive some areas were identified. Examples include:

- community recording
- dental and optometry records
- screening programmes
- patient entered health data (e.g. from wearables)
- further work on end of life care plans

- outcomes recording (<https://www.ichom.org/>)
- social determinants of health

The original scope of the core information set included a requirement to be able to link to genetics reports. Whilst the standard supports links to genetic reports in the form of a PDF, it may not support structured genetic information which may be a requirement for the future.

Although this version of the core information standard is an important baseline that will enable progress to be made, it is recognised that further work is needed in some areas and the standard will evolve as it is trialled in practice.

### **Recommendations**

12. Develop a consensus-based national metadata standard for documents and images for use across the four nations that can then be applied to the core information standard.
13. Scope a future programme of work, investigating the inclusion of the information content identified in the consultation as missing from the current version of the core information standard. Feedback should also be obtained from trialling the standard and incorporated into any future work programme.
14. PRSB should review existing standards in light of the development of the core information standard to align existing standards with this standard.

## 10 Appendix A datasets

While the detailed content of the longitudinal record will evolve over time, there are some key data items which are expected to be included as part of an individual record and form the basis of the initial longitudinal record. The data required to populate the initial longitudinal record may be drawn a variety of sources including national and local systems.

### Data

A longitudinal record is expecting to address the following common core datasets

- Demographics
- Examinations
- Care plans
- Procedures
- Assessments
- Diagnoses
- Allergies
- Investigations
- Correspondence
- Problems
- Medication
- End of life plans
- Social care
- Link to genomic reports<sup>1</sup>

The detail of this content of each of these datasets will be progressively defined through a process of Exemplar collaboration, and subject to appropriate assurance to ensure that they comply with the information governance framework.

In addition, we expect that there will be additional datasets which extend the common core and which are associated with specific care pathways including, but not limited to,

- Cancer
- Maternity
- Mental health
- Urgent and emergency care
- Patient data

Subject to further discussion and agreement, and in line with meeting the requirements of the information governance framework and in particular meeting requirements for a clear

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<sup>1</sup> This is a specific data class requirement and is expected to simply include link to reports held elsewhere rather than detail.

legal basis for collection and sharing, the record may extend over time to include datasets relating to

- Specialist clinical content
- Clinical research related data
- Patient provided data
- Data relating to the wider determinants of health for an individual – e.g. housing, education etc.

In addition, we would anticipate LHCREs developing their plans for populating the longitudinal record from existing digitised sources including, but not limited to:

- Historic data reported to SUS/HES including
  - historic diagnoses
  - historic procedures
  - past appointments
- Data in near real-time including
  - pathology results, medications, image reporting
  - waiting list additions
  - hospital admissions and discharges
- The full record from GPs and other digitised care settings

## 11 Appendix B the core information standard



Core information  
standard 260619 web



## 12 Appendix C reference materials

1. Greater Manchester Core Dataset - Defining the Data sets for Organisations (GM Core Dataset Definition 20170620)
2. PRSB Standards for the Structure and Content of Health and Care Records (the PRSB standards) (<https://theprsb.org/standards/healthandcarerecords/> )
3. Summary Care Record (<https://digital.nhs.uk/services/summary-care-records-scr>)
4. International Patient Summary (<https://art-decor.org/art-decor/decor-project--hl7ips->)
5. Medical Interoperability Gateway (<https://healthcaregateway.co.uk/services/detailed-care-record/>)
6. USA care co-ordination standard (<https://corepointhealth.com/resource-center/white-papers/understanding-continuity-care-record/>)
7. [https://en.wikipedia.org/wiki/Continuity\\_of\\_Care\\_Record](https://en.wikipedia.org/wiki/Continuity_of_Care_Record))
8. Scottish Emergency Care Record and the Key Information Summary (<https://www.nhslothian.scot.nhs.uk/GP/InverleithMedicalPractice/EmergencyCareSummary/Pages/default.aspx>)
9. Welsh GP record (<http://www.gprecord.wales.nhs.uk/what>)
10. Northern Ireland Emergency Care Summary, Electronic Care Record and Key Information Summary (<https://www.nidirect.gov.uk/articles/northern-ireland-electronic-care-record-niecr>)
11. People in control of their own health and care ( the Kings Fund) ([https://www.kingsfund.org.uk/sites/default/files/field/field\\_publication\\_file/people-in-control-of-their-own-health-and-care-the-state-of-involvement-november-2014.pdf](https://www.kingsfund.org.uk/sites/default/files/field/field_publication_file/people-in-control-of-their-own-health-and-care-the-state-of-involvement-november-2014.pdf))
12. Personalised Health and Care 2020: Using Data and Technology to Transform Outcomes for Patients and Citizens. A framework for action by the National Information Board ([https://www.digitalhealth.net/includes/images/news0254/PDF/0172\\_NHS\\_England\\_NIB\\_Report\\_WITH\\_ADDITIONAL\\_MATERIAL\\_S8.pdf](https://www.digitalhealth.net/includes/images/news0254/PDF/0172_NHS_England_NIB_Report_WITH_ADDITIONAL_MATERIAL_S8.pdf))
13. Joined Up Leeds: Understanding the views of individuals in Leeds on a Personal Health Record by Brainbox Research (<https://www.leedsccg.nhs.uk/content/uploads/2018/05/Summary-Joined-Up-Leeds-report-1.pdf>)
14. Personal health record (PHR) User insights by the Health Informatics Unit, Royal College of physicians (<https://www.rcplondon.ac.uk/projects/outputs/personal-health-record-phr-user-insights>)

15. Personal Health Record Discovery Report by NHS Digital (<https://digital.nhs.uk/services/personal-health-records-adoption-service/personal-health-records-adoption-toolkit>)
16. Personal Health Records: Learning from voices of experience by Patient Information Forum (<https://www.pifonline.org.uk/wp-content/uploads/2017/01/PIF-PHR-Guide-2017-V2.pdf>)
17. Personal Health Records: Putting patients in control? by 2020health.org ([www.2020health.org/2020health/policy/Policy-A-Z/Patients.html](http://www.2020health.org/2020health/policy/Policy-A-Z/Patients.html))
18. A Blueprint for a co-produced Personal Health Record (CoPHR) Ecosystem by Apperta Foundation ([https://apperta.org/assets/Apperta\\_A\\_Blueprint\\_for\\_a\\_Co-produced\\_Personal\\_Health\\_Record\\_Ecosystem.pdf](https://apperta.org/assets/Apperta_A_Blueprint_for_a_Co-produced_Personal_Health_Record_Ecosystem.pdf))
19. Documenting Routinely What Matters to People: Standardized Headings for Health Records of Patients with Chronic Health Conditions by Birgit Prodinge, Paul Rastall, Dipak Kalra, Darren Wooldridge & Iain Carpenter (<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5966302/>)
20. Personal Health Record (PHR) Landscape Review by the Health Informatics Unit, Royal College of physicians (<https://www.rcplondon.ac.uk/projects/outputs/personal-health-record-phr-landscape-review>)
21. Personal Health Records: A Systematic Literature Review by Alex Roehrs, Cristiano André da Costa, Rodrigo da Rosa Righi & Kleinner Silva Farias de Oliveira (<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5251169/>)
22. Technical specifications: EMIS, Vision, TPP, e-Referral service data dictionary, Appointment FHIR, Discovery data service core health set
23. Local Authority data sets: Thames Valley & Surrey - full specifications for adult and child, Greater Manchester - full specifications for adult and child, OneLondon (Newham, Camden), Cheshire Care Record
24. Leeds Care Record (high level information provided by Leeds Care Record team)
25. Information Sharing with Care Homes, PRSB (<https://theprsb.org/projects/carehomereport/>)
26. End of Life data sets: End of life minimum dataset (NHS Digital), ReSPECT, Co-ordinate My Care, The Future Planning Project
27. Crisis care summary, PRSB (<https://theprsb.org/standards/crisiscare/>)
28. Maternity record standard, PRSB (<https://theprsb.org/standards/maternityrecord/>)
29. Healthy child record, PRSB (<https://theprsb.org/standards/healthychildrecordstandard/>)

30. Royal College of Emergency Medicine "Mental health clerking detail is commonly poor in ED notes, and without a prompt it is unlikely that doctors will record the key findings that inform risk."  
(<https://www.rcem.ac.uk/docs/RCEM%20Guidance/Mental%20Health%20Toolkit%202017.pdf>)
31. NICE guidance e.g. Self Harm in ED (<https://pathways.nice.org.uk/pathways/self-harm#path=view%3A/pathways/self-harm/psychosocial-assessment-of-self-harm-in-the-emergency-department.xml&content=view-index>)
32. MIND guidance for people suffering mental health crisis  
(<https://www.mind.org.uk/information-support/guides-to-support-and-services/crisis-services/accident-emergency-ae/#.XFrFFdL7TtQ>)
33. RCPsych standards and guidance (<https://www.rcpsych.ac.uk/members/your-faculties/liaison-psychiatry/news-and-resources>)
34. MHSDS (<https://digital.nhs.uk/data-and-information/data-collections-and-data-sets/data-sets/mental-health-services-data-set>)
35. RiO Clinical downtime forms – SWL&St George's
36. Care Notes data model (ACS)
37. System 1 data model (SABP)

## 13 Appendix D consultees during the discovery phase

Consultees	Name
Cambridge University Hospitals NHS Foundation Trust	Afzal Chaudhry
CWP NHS Foundation Trust	Adrian Burke
Endeavour Health Charitable Trust	David Stables
Ex geriatrician, PRSB	Iain Carpenter
GP, PRSB	Phil Koczan
Greater Manchester Health & Social Care Partnership	Paul Moore
Hull and East Yorkshire Hospitals NHS Trust	Mark Simpson
Leeds Care Record	Julia Millman
Local Government Association	Mark Golledge
NHS Digital	Nicholas Oughtibridge
NHS Digital	Robert Jeeves
NHS Digital	Marian Tilley
NHS Digital	Keith Strahan
NHS Digital	Mark Nicholas
NHS Digital	James Palmer
NHS Dorset Clinical Commissioning Group	Andy Hadley
NHS England	Ian Townend
NHS South, Central and West Commissioning Support Unit (CHIE)	Peter Cambouropoulos
OneLondon	Jo Fulton
Patient advisor, PRSB	Laura Fulcher
Patient and Public Engagement Adviser PRSB, Expert Advisory Committee SCR	Judith Brodie
Patient Information Forum	Sophie Randall
Royal College of Nursing	Matt Butler
Salford Royal NHS FT	Scott Watson
Salford Royal NHS FT	Rebecca Fletcher
Salford Royal NHS FT	Tim Pattison
Sheffield Teaching Hospitals NHS Foundation Trust	Karen Selby
Southern Health NHS FT	Lisa Franklin
Surrey Heartlands (Surrey Care Record)	Kat Stolworthy
Thames Valley and Surrey Local Health & Care Records programme	Andrew Fenton
Tower Hamlets CCG	Bill Jenks
University of Portsmouth	Philip Scott
Yorkshire and Humber Care Record Programme	Lee Rickles

## 14 Appendix E project advisors

<b>Project Advisor Role</b>	<b>Name</b>
General Practitioner	John Robinson
General Practitioner	Phil Koczan
Hospital Doctor	Iain Carpenter
Mental Health Care Professional	Matt Butler
Patient Lead	Laura Fulcher
Social Care Professional	Tommy Reay

## 15 Appendix F project stakeholder groups

### Key groups of project stakeholders

#### 1. Patients, carers, citizens and service users

This primarily included representatives from the appropriate member organisations.

#### 2. The LHCR teams

This primarily included the members of the Clinical Advisory Group but also programme managers, other clinicians, patient representatives, representatives from social services, and clinical informaticians who we are directed to because of this work. Identification of stakeholders within the LHCR teams will occur after initial introduction to the clinical leads.

#### 3. Key vendors

This primarily included representatives from the appropriate member organisations. This would include system vendors supporting the LHCR localities and other key vendors (from the HSSF).

#### 4. NHS Digital

The national business and functional architecture team and terminology groups to ensure awareness of this work and alignment.

#### 5. Public Health England

Engagement to raise awareness of the project, to support future implementation.

### PRSB member organisations

#### Academy of Medical Royal Colleges

- Academy of Medical Royal Colleges
- Royal College of Anaesthetists
- Royal College of Emergency Medicine
- Royal College of General Practitioners
- Royal College of Obstetricians & Gynaecologists
- Royal College of Ophthalmologists
- Royal College of Paediatrics and Child Health
- Royal College of Pathologists
- Royal College of Physicians
- Royal College of Psychiatrists
- Royal College of Radiologists
- Royal College of Surgeons

### **Allied Health Professional Federation**

- Allied Health Professionals Federation
- Allied Health Professionals Scotland
- British Association for Music Therapy
- British Dietetic Association
- Chartered Society of Physiotherapy
- Royal College of Occupational Therapists
- Royal College of Speech and Language Therapists

### **Clinical**

- British Orthodontics Society
- British Psychological Society
- Faculty of Clinical Informatics
- Queen's Nursing Institute
- Resuscitation UK
- Royal College of Midwives
- Royal College of Nursing
- Royal Pharmaceutical Society

### **Social Care**

- Association of Directors of Adult Social Services
- Association of Directors of Children's Social Services
- Care Provider Alliance
- Chief Social Worker
- Community Practitioners and Health Visitors Association

### **Patient Organisations**

- Compassion in Dying
- National Voices

- Patient Information Forum

### **Technology**

- BCS Health and Care
- HL7 UK
- Institute of Health Records Information Management (IHRIM)
- INTEROPen
- Tech UK

### **Regulators**

- National Institute for Health and Care Excellence (NICE)

### **Government**

- Public Health England

### **Four Nations Governments**

- Northern Ireland
- Scotland
- Wales

### **International**

- eHealth Ireland

### **Other Stakeholder Organisations**

- Association for Palliative Medicine
- Association for Young Peoples' Health
- Association of Cancer Physicians
- Association of Child and Adolescent Mental Health
- Association of Paediatric Emergency Medicine
- BCS Health
- British & Irish Orthoptic Society
- British Association of Perinatal Medicine



- British Dental Association
- British Geriatrics Society
- British Medical Association
- British Pharmacological Society
- Carers Trust
- Carers UK
- Chief Information Officers Network
- Coalition for Collective Care
- College of Paramedics
- Dementia UK
- Diabetes UK
- Faculty of Intensive Care Medicine
- Four Nations Government NI
- Four Nations Government Scotland
- Four Nations Government Wales
- Genetic Alliance
- Genomics England
- Hospice UK
- International Alliance of Patients' Organisations
- LHCR Greater Manchester
- LHCR London
- LHCR Thames Valley and Surrey
- LHCR Wessex
- LHCR Yorkshire and Humber
- Local Government Association
- Macmillan Cancer Support
- Mental Health Nurses Association
- NHS Clinical Commissioners (NHSCC)

- NHS Digital
- NHS Digital Vendor Network
- NHS England
- PRSB Advisory Board Nominee
- RCP Patient Network
- Royal College of General Practitioners Informatics Group
- The Association of UK Dieticians

#### Other Networks

- Chief Clinical Information Officers Network

## 16 Appendix G consultation themes and questions (focus group and webinars)

Aims	Participants	Consultation questions/themes	Other considerations
<b>Citizen focus group</b>			
<p>Understand needs, priorities and preferences of people</p> <p>Ensuring the information enables and encourages greater self-management of care</p>	<p>Focus group discussion with six to 10 people who use services and carers to understand their priorities plus, and multi-disciplinary professionals.</p>	<p>Participants were asked to complete examples of where they have experienced issues with information sharing and to propose solutions on how this could be improved. These were stuck to the walls and participants asked to identify key themes and solutions on post-it notes for each experience and these were then aggregated into common themes and proposals.</p>	
<b>People using services and their carers webinar</b>			
<p>Understand needs, priorities and preferences of people ensuring the information enables and encourages greater self-management of care</p>	<p>Webinar with people who use services, their carers and multi-disciplinary professionals.</p>	<p>What would you like to contribute to your health &amp; wellbeing information?</p> <p>If you had a section of information dedicated to you, what would be in it?</p> <p>How could this core information enable you to gain more autonomy and reduce the burden and anxiety of being a 'patient'?</p> <p>How could the core information provide next steps in your treatment journey?</p> <p>How could the core information record what is most pertinent to you, and what you want to be dealt with?</p>	

		<p>What might you need to see from the past and how might that be helpful? e.g. past appointments, discharge summaries from previous admissions etc.</p> <p>How could the core information facilitate better communication?</p> <p>What information could you anticipate not wanting to share with a carer?</p> <p>What support would you need to decide what information a carer should be able to see?</p> <p>How could the core information support carers to fulfil their role?</p> <p>How could the core information support carers to fulfil their role?</p> <p>If you could access your results, how and when would you like to receive them?</p> <p>What documents would you like to access?</p> <p>e.g. Letters, scans, discharge summaries, results, pathology reports etc.</p>	
<b>Social care</b>			
<p>Identify what information should be stored, for what purpose and how in relation to social care.</p>	<p>Led by social care specialist advisor. Social care professionals, providers of care, people who use social care services and carers, as well as clinicians.</p>	<p>Social care professionals, providers of care and people who use services as well as clinicians were asked if data requirements of councils, home care agencies, nursing homes, residential homes and supported living schemes radically different from each other.</p> <p>What does the health-aspect of social care need from health and social care?</p> <p>Language-wise what is lost in translation between health and social care?</p> <p>Child social care information seems to focus on:</p> <ul style="list-style-type: none"> <li>• Safeguarding</li> </ul>	<p>Social care is a broad area with different needs for local authorities, care providers and domiciliary care. Working with LGA/SOCITM to elicit LA and Care Provider Support Service to identify needs of care providers.</p>

		<ul style="list-style-type: none"> <li>Flags e.g. team around the child, special educational needs etc.</li> </ul> <p>What else should be included?</p> <p>How could the PRSB better engage with child social care providers?</p> <p>When someone stops receiving social care support, after closing the case what should remain in the core information?</p> <p>Should safeguarding be part of the core information?</p> <p>How much information should be available?</p> <p>How should disabilities be recorded?</p> <p>Should temporary disabilities be recorded? e.g. post-operative recovery, side-effects from treatment</p> <p>Do social care providers see value in including the primary support reason in the core information?</p> <p>Where could primary support reason sit as a data field?</p> <p>Should the core information include the details of organisations involved in supporting the individual:</p> <ul style="list-style-type: none"> <li>If the organisation cannot access or add to the core information?</li> </ul> <p>If there is no supporting context provided, e.g. team around the family (TAF), educational services?</p> <p>Should the core information include whether the individual is being supported by a local care initiative, which may not be relevant outside of their immediate area?</p>	
<b>Mental Health</b>			

To identify elements of existing standards that should be included in the core	Led by MH specialist advisor, MHS professionals, BPS network	Five scenarios were shared with the mental health professionals, psychologists and users of services/carers during this consultation and the following questions were asked in regard to each: <ul style="list-style-type: none"> <li>• What information does this person need in this care setting?</li> <li>• What's missing from this picture/scenario?</li> <li>• What else is there?</li> <li>• What other benefits/ uses could there be?</li> </ul>	
<b>Encounters, alerts, appointments and test orders</b>			
Identify what information should be stored, for what purpose and how in relation to events	Technical architects informaticians, clinicians and service users for what purpose and how in relation to events etc.	Clinicians and people who use services were asked what set of information related to events, alerts etc. should be recorded and at what level of detail for retrospective data collection and prospective use.	
<b>End of life</b>			
Identify what information should be stored, for what purpose and how in relation to end of life care.		Clinicians, social care professionals, carers and people using health and care services were asked the following questions as part of the consultation: What information do individuals, carers and professionals involved in end of life care think is most valuable? What are the clinical issues affecting how information is captured and viewed? How will patients and carers be affected through sharing the core information?	Different place EOL information is represented in the standard?

		<p>What are the benefits?</p> <p>What are the risks?</p> <p>Do you think a primary diagnosis indicator should be part of the core information?</p> <p>Should the core information include the details of organisations involved in supporting the individual:</p> <p>If the organisation cannot access or add to the core information?</p> <p>If there is no supporting context provided e.g. educational services?</p> <p>Should the core information include whether the individual is being supported by a local care initiative, which may not be relevant outside of their immediate area?</p> <p>Is 'end of life' an appropriate name for this section? What could it be named instead?</p> <p>What information should be recorded about certification of death?</p>	
<b>Maternity and child health</b>			
To identify elements of existing standards that should be included in the core.		<p>Clinicians and women attending the consultation will be asked the following questions:</p> <p>Should the whole healthy child record be available from the core record whilst you are a child, similarly with the maternity record for pregnant women?</p> <p>What elements of the healthy child record would need to stay in the core record when the young person transitions to adult services?</p> <p>Should the maternity record continue to be routinely available after the pregnancy outcome and, if so, for how long?</p>	

		<p>What elements of the maternity record may be relevant to a pregnant woman who presents to a healthcare professional for something not directly relevant to her maternity care?</p> <p>Should safeguarding concerns be included in the LHCR record, which is available to all health care professionals and patients?</p> <p>Should detailed pregnancy outcome delivery and birth information be included in the core record or just the obstetric history of the maternity record?</p> <p>Is blood transfusion history / refusal of blood transfusion relevant for a core record?</p> <p>Should the “Immunisations” section be renamed “vaccinations”?</p> <p>In the family history section, the core record does not include a heading for maternal medical conditions or infectious diseases arising in pregnancy which may have an impact on the foetus – would this be relevant to include?</p> <p>Should local authority for the child protection plan and looked after child status be included in the core record?</p>	
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## 17 Appendix H Webinar and focus group attendees

End of life webinar

Organisation	Name
ADASS	David Watts
Barts Health NHS Trust	Philippa Evans
Carer	Ann Richardson
CareWorks	Martin Hanlon
Compassion in Dying	Upeka de Silva
Compassion in Dying	Zach Moss
Coordinate My Care	Julia Riley
Dorset Care Record	Ellie Venton
DXC Technology	Rhona Dalziel
Graphnet	Dawn Boswell-Challand
Greater Manchester & Eastern Cheshire End of Life Care	Christine Taylor
LAS and Healthy London Partnership	Briony Sloper
Log my Care	Sam Hussain
London Ambulance Service	Frank Neaves
Macmillan	Jo Keyes
Macmillan	Jo Keyes
Marches Care	Mandy Thorn
Mountbatten	Richard Eason
NHS England	Eileen Mitchell
NHS England	Joanne Brooks
NHS England	Rhodri Joyce
NHS England	Diana Robinson
NHS England	Irene Mitchell
NHS Lincolnshire East CCG	Sue Jarvis
North East London NHS Foundation Trust	Phil Koczan
Patient Information Forum	Sophie Randall
Patients and Public	Alan Craig
PRSB	James Burton
PRSB	Kasmyn Chen
PRSB	Martin Orton
PRSB	Pauline Swan
PRSB	Sandip Kaur
PRSB Clinical Advisor	Iain Carpenter
Resuscitation Council	Rachel Warren
Royal College of Physicians HIU	Jan Hoogewerf
Royal College of Physicians HIU	Lindsay Dytham
Salisbury District Hospital	Suzie Neaves
SOCITM	Abbas Awan
South Tyneside NHS Foundation Trust	Edward Nowicki

Southern Health NHS Foundation Trust	Steve Plenderleith
St Barnabas Hospice	Lawrence Pike
Surrey and Borders Partnership NHS Foundation trust	Doug Stewart
The Royal British Legion	Alan Downey
The Royal British Legion	Ian Cooper
The Royal British Legion	Sharon Devi

People using services and their carers webinar

Organisation	Name
8 foldhealth	Lyndon Johnson
Accessible Info	Howard Leicester
Carer	Sabin Qureshi
Dorset Care Record	Ellie Venton
Graphnet	Dawn Boswell-Challand
Graphnet	Qaez Anwar
Graphnet	Dawn Boswell-Challand
Graphnet	Qaez Anwar
Greater Manchester Health and Social Care Partnership	Stephen Dobson
Health One Global	Stanley Shepherd
MIND	Paul Ward
NHS Connecting for Health	Miles Gray
NHS Digital	Simon Rose
NHS Digital PHR Programme	Andy Payne
NHS England	John Farenden
NHS England	Diana Robinson
Patient Information Forum	Sophie Randall
Patients and Public	Alan Craig
Patients and Public	Kalina Zaborowska
Patients and Public	Ron Newall
Patients and Public	Suzanne Elsworth
Patients and Public	Patrick Ojeer
Patients Know Best	Shailesh Suri
PRSB	Alannah McGovern
PRSB	Helene Feger
PRSB	Kasmyn Chen
PRSB	Pauline Swan
PRSB Carer	Holly Kearn
PRSB Clinical Advisor	Laura Fulcher
Resuscitation Council	Rachel Warren
Royal College of Physicians HIU	Nicola Quinn

Social care webinar

Organisation	Name
ADASS	David Watts
Alzheimer's society	Francesca Markland
BCS	Andy Kinnear
Care Provider Alliance	Ian Turner
co4cc	Laura Bimpson
Community Integrated Care	Jason Hengler
Dorset County Council	Brian Hole
Graphnet	Barry Keown
Graphnet	Dawn Boswell-Challand
Health and Social Care Alliance	Zahid Deen
Health One Global	Stanley Shepherd
Heart of England Mencap	Ali Arnold
Imperial College Healthcare NHS Trust	Stephen Janering
LHCR Yorkshire and Humber	Neil Bartram
Local Government Association	Mark Golledge
NHS Digital	Keith Strahan
NHS South Central and West CSU	Gary McKelvey
Norse Care	Ben Meen
PossAbilities CIC	Amanda Higgs
PRSB	Kasmyn Chen
PRSB	Sandip Kaur
PRSB	Sarah Jackson
PRSB Clinical Advisor	Iain Carpenter
Royal College of Physicians HIU	Nicola Quinn
SeeAbility	Donna O'Brien
Skills for care	Rob Hargreaves
SOCITM	Russ Charlesworth
Southern Health	Steve Plenderleith
Surrey County Council	Claire White
The Royal British Legion	Ian Cooper
Trafford Council	Paul Dean

Mental health webinar

Organisation	Name
Graphnet	Qaez Anwar
Graphnet	Dawn Boswell-Challand
MIND	Rachel Boyd
MIND	Rachel Boyd
NHS Digital	Ian Binns
NHS England	Hilary Tovey
Oxleas NHS Foundation Trust	James Woollard

Park Medical Centre, Cambridge	Janice Allister
Patient and Public	Meg Hunt
PRSB	James Burton
PRSB	Martin Orton
PRSB	Helene Feger
PRSB	Sarah Jackson
PRSB	Annette Gilmore
RCGP	Jill Rasmussen
Remind me Care	Simon Hooper
Royal College of Nursing	Matt Butler
Royal College of Psychiatrists	Sarah Hickling
SLAM	Nicola Byrne
West Midlands Academic Health Science Network	Sarah Appleby

#### Maternity and healthy child webinar

Organisation	Name
Cambio Healthcare	Tina Hanlon
Carer	Sabin Qureshi
CSC	Rhona Dalziel
East Suffolk And North Essex NHS Foundation Trust	John Lamont
K2 Medical Systems	Kate Jamieson
Medway NHS Foundation Trust	Vicki Gannon
Medway NHS Foundation Trust	Andrea curling
NHS Digital	Sarah Ashcroft
NHS Digital	Chris Dickson
NHS England	Rhodri Joyce
NHS England	Steven Dodd
NHS South, Central and West CSU	Natasha Neads
Oxford Health	Victoria Kirby
Park Medical Centre - Cambridge	Janice Allister
Patients and Public	Natalie Leal
Patients and Public	Emily Roberts
Poole Hospital NHS Trust	Dawn Jackson
PRSB	Alannah McGovern
PRSB	Helene Feger
PRSB	James Burton
Public Health England	David Elliman
RCOG	Karen Selby
Resuscitation Council	Rachel Warren
Royal College of Physicians HIU	Lindsay Dytham
Royal Surrey County Hospital NHS Foundation Trust	Alison Wooderson
West Midlands Academic Health Science Network	Sarah Appleby
West Midlands Academic Health Science Network	Elaine Russell

Encounters, alerts, appointments and test orders webinar

Organisation	Name
Endeavour Health Charitable Trust	David Stables
Graphnet	Dawn Boswell-Challand
Greater Manchester Health and Social Care Partnership	Malcolm Mundy
Leeds teaching hospitals NHS trust	Daniel Wootton
Leeds teaching hospitals NHS trust	Nigel Hodgson
NHS Dorset CCG	Andy Hadley
NHS England	John Robinson
PRSB	Alannah McGovern
PRSB	James Burton
PRSB	Sarah Jackson
PRSB	Sandip Kaur
PRSB Clinical Advisor	Iain Carpenter
Royal College of Physicians HIU	Jan Hoogewerf
Yorkshire and Humber Care Record Programme	Tony Shannon

Citizen focus group

Representing	Name
Patients	Geoffrey Entwistle
Patients & Carers	Ceri McDade
PRSB	Kasmin Chen
PRSB	Pauline Swan
PRSB Patient Lead and self	Laura Fulcher
RCP Patient Carer Network and self	Richard Triffit
Self	Nannette Spain
Self	Ron Newell
Self	Patrick Ojeer
Self	John March
Self - but involved with many organisations	Victor Boulter
Self & family	Mary Mulwila
Self & family, useMYdata, variety of research	Margaret Johnson
UNTRAP; CLROVWN; PILAR; carers	Andrew Entwistle

## 18 Appendix I consultation themes and questions (workshop)

Aims	Participants	Consultation questions/themes	Other considerations
<b>Core Information</b>	<b>All</b>		
<p>Test the core standard is understood and deemed useful. To determine what information needs to be shared and the practical benefits and potential consequences of doing so.</p>		<p><b>Workshop attendees were asked the following questions, which are based on a number of scenarios that were posed to the group.</b></p> <p>Does the core information meet the needs and enable better care in the scenario you have been given?</p> <ul style="list-style-type: none"> <li>- For professionals delivering services?</li> <li>- For people using services?</li> </ul> <p>Which parts of the core information will be particularly valuable in this scenario and why? What are the risks of not sharing this information to a person's safe care and outcomes?</p> <p>Is all the core information needed (according to the criteria discussed)? What information is missing and why is it needed?</p> <p>What are the most important areas of core information that should be shared, e.g. clinical data for emergency care? Functional data for care of the elderly? Risk assessments for mental health crisis care? Person-centred data such as about me, wellbeing data, functional abilities? What are the risks and challenges you see in this information being shared?</p> <p>The scenarios for session two describe people with specific needs for health and social care support. Does this change what should be included in the core information about these users of services in order to support safe and effective care?</p>	

		<p>How would it help a person take more control of their own health and care? How could it help an informal carer or a third sector provider of care?</p> <p>In what situations would it be useful to see social care narrative assessments rather than the fact that an assessment has taken place?</p> <p>Do you have any concerns about sharing the information? How could those concerns be addressed?</p> <p>Should core information include patient/user collected data, goals?</p> <p>How should this information be used in providing care?</p> <p>Should the core include more information to help people to better understand their medications?</p> <p>What information should be in the core information set on temporary or permanent disability? PRSB standards currently include accessibility information.</p> <p>What types of patient-provided information such as values, goals, functional ability, wellbeing is useful in a mental health setting?</p> <p>Should genetic test information be included in core information or flagged?</p> <p>Is there any core information that needs to be collected after death? Is it necessary to include it in the core information?</p> <p>Is primary support reason (e.g. a physical health issue that requires social care support and is recorded by social care) useful for health care professionals?</p> <p>Should anything identified as abnormal be part of the core information – how do we identify what is abnormal? (e.g. high blood pressure during pregnancy)</p> <p>Should safeguarding information be included as core information?</p>	
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		Should developmental skills remain part of core information after a child with special needs transitions to adult care?	
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## 19 Appendix J workshop attendees

Organisation	Name
Carer	Amanda Rudczenko
co4cc	Laura Bimpson
Compassion in Dying	Natalie Koussa
Faculty of Clinical Informatics	John Williams
Genomics England	Amanda O'Neill
Guy's and St Thomas'	Gary McAllister
Gwent and South Powys	Julian Costello
Royal College of Physicians	Jan Hoogewerf
IHRIM	Kim Bellis
IMS Maxims	Michael Thick
LHCR Greater Manchester	Gareth Thomas
Local Government Association	Mark Golledge
Macmillan	Rebecca Wellburn
Macmillan	Samuel Dick
Marches Care	Mandy Thorn
NHS Digital	Keith Strahan
NHS Digital PHR Programme	Andy Payne
NHS Dorset CCG	Andy Hadley
NHS England	John Farenden
NHS England	Oliver Benson
NHS North West Surrey CCG	Kat Stolworthy
NHS South, Central and West CSU	Andrew Fenton
NUH	Michael Azad
Oxleas NHS Foundation Trust	James Woollard
Patients and Public	Alan Craig
Patients and Public	Andrew Entwistle
Patients and Public	Annie Makowf-Clark
Patients and Public	Geoffrey Entwistle
Patients and Public	Manjit Johal
Personalised Care Group, NHS England	Jo Harvey
PHE	Clare Jones
PIF	Sophie Randall
PRSB	Alannah McGovern
PRSB	Maureen Baker
PRSB	Annette Gilmore
PRSB	Helene Feger
PRSB	James Burton
PRSB	Kasmyn Chen
PRSB	Lorraine Foley
PRSB	Pauline Swan
PRSB	Sandip Kaur

PRSB	Sarah Jackson
PRSB	Lizzie Cernik
PRSB Clinical Adviser	Iain Carpenter
PRSB Clinical Adviser	John Robinson
PRSB Clinical Adviser	Phil Koczan
PRSB Patient Lead	Laura Fulcher
PRSB/ Carer	Holly Kearn
Public Health Agency	Claire Buchner
RCOT	Suzy England
RCP	Matt Butler
RCP HIU	Lindsay Dytham
RCPCH	David Low
RCSLT	Kathryn Cann
Royal College of Psychiatrists	Laurie Beed
Royal Free London NHS FT	Maria McCrann
RPharmS	Stephen Goundrey-Smith
Scottish government	Steve Baguley
SLAM	Omer Moghraby
SLAM	Nicola Bryne
SOCITM	Russ Charlesworth
Southampton CCG	Mark Kelsey
West London Mental Health Trust	Jonathan Scott
Yorkshire and Humber Care Record Programme	Tony Shannon
Yorkshire and Humber Care Record Programme	Lee Rickles

## 20 Appendix K survey design

Aims	Participants	Consultation questions/themes	Other considerations
<b>Survey</b>			
<p>To test a draft of the core information standard model with a wide group of service users and care providers.</p>	<p><b>All</b></p>	<ol style="list-style-type: none"> <li>1. Please tell us your role.</li> <li>2. Please describe the setting in which you work.</li> <li>3. Do you agree that sharing core information will bring these benefits? <ul style="list-style-type: none"> <li>-Improve the quality and safety of care</li> <li>-Make care more efficient</li> <li>-Lead to better integration between services</li> <li>-Support people to take more control and manage their own care</li> <li>-Support better care planning and research</li> </ul> </li> <li>4. What concerns do you have about sharing core information?</li> <li>5. Which of the following benefits would people who use services get from contributing to the information held in their health and care records? For example, recording their needs, values and preferences or measurements they have taken such as blood pressure. <ul style="list-style-type: none"> <li>-Improve communication including the timeliness of information sharing e.g. sharing test results</li> <li>- Promote people managing their own care</li> <li>-Support making joint decisions with professionals about their care</li> <li>-Improve efficiency, e.g. avoid repeating information</li> <li>-Reduce burden on professionals</li> </ul> </li> </ol>	

		<p>-Improve safety</p> <p>6. Can you see any issues arising as a result of people who use services contributing to and sharing their information?</p> <p>7. Please rate how important this information is to you. Think about what information it would be helpful to know that you can't currently access.</p> <p>-About me</p> <p>-Demographics and contacts</p> <p>-Legal Information</p> <p>-Social context</p> <p>-Family history</p> <p>-Relevant past history</p> <p>-Pregnancy status</p> <p>-Safeguarding and risks</p> <p>-Medications and allergies</p> <p>Investigations, examinations and assessments</p> <p>-Problems, diagnoses, conditions and procedures</p> <p>-Plan and requested actions</p> <p>for professionals and the person, including investigations and treatments</p> <p>-Vaccinations</p> <p>-Developmental skills</p> <p>-Participation in research</p> <p>-Alerts</p> <p>8. What if anything is missing from the above list?</p>	
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		<p>9. Should 'about me' be prioritised as part of the core information for everyone involved in health and care?</p> <p>10. Should alerts (e.g. metallic implant, dangerous dogs) be flagged as part of the core information set?</p> <p>11. Should assessment summaries (which include written assessment outcomes for social care and mental health) be included in the core information set?</p> <p>12. This subsection is called risks. Does 'risks' describe this section well and is this what you would expect to see in it?</p> <p>13. Date, location, performing professional, Gynaecology, past obstetric: is this all the information you need to share as part of the core information set about an individual's past pregnancy history?</p> <p>14. Should current pregnancy status be part of the core information set?</p> <p>15. Should the core information set include correspondence such as outpatient letters or letters from patients?</p> <p>16. Should the core information set include details of historic (now closed) child protection plans? (A child protection plan acts to keep a child safe from abuse and neglect.)</p> <p>17. Should disability be included as a separate section in the core information set? (Mobility, cognitive and accessibility disabilities are currently recorded in individual requirements)</p> <p>18. Is this all the information needed for end of life care as part of the core information set?</p> <p>19. Do you have any other comments you would like to add before submitting the survey?</p>	
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## 21 Appendix L expert review group (attendees)

Expert Group Role	Name
Consultant Psychiatrist & CCIO & clinical informatician	James Reed
Emergency care physician	Tony Shannon
Ex geriatrician & clinical informatician	Iain Carpenter
Ex GP & expert clinical informatician	Ian McNicoll
Ex GP, Newcastle Uni & clinical informatician	Nick Booth
General Practitioner	John Robinson
General Practitioner & clinical informatician	Phil Koczan
MH Nurse & clinical informatician	Matt Butler
North Yorks county council, LHCR (social care)	Neil Bartram
Physio (AHP)	Euan McComiskie
Renal physician, CCIO & clinical informatician	Afzal Chaudhry
Surgeon & CCIO	Dermott O' Riordan

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## 22 Appendix M expert review group questions

Questions from the first expert review group meeting (1 May 2019)

### General questions

1. Does the overall structure of the model make sense to you?
2. Is anything included that you don't think is necessary for the first release?
3. Retaining the clinical context of the information has been raised as a clinical safety risk. The maternity shared record work introduced the use of the following elements to provide some contextual information:
  - Performing professional (the professional linked to the record entry)
  - Date (the date of the activity day/month/year, e.g. the date that the procedure took place)
  - Location (the organisation/institution at which the activity took place e.g. the hospital at which the procedure took place)

Is performing professional required as we don't know what it is – for example when testing blood – is the performing professional the person who ordered the test, the person who took the sample, the clinical scientist who actually performed the assay or the consultant / GP responsible for the order at a senior level – or perhaps all of these? Should specialty be added as an additional contextual data item?

4. An additional concern raised, related to question three above, is that the information model does not articulate the links between the different types of information. For example, a diagnosis would be linked to an encounter/consultation and a diagnosis may be linked to an investigation result or an assessment. It has been discussed that in order to be clinically safe, these links need to be articulated in the model. However, links between information types may depend on use cases and this information model is designed to be generic and should apply to multiple use cases. What are your views on whether the links should be defined in the PRSB information model?
5. The principles we have used to define whether a section, cluster or element is mandatory, required or optional are as follows:
  - Minimise the number of mandatory data items.
  - The only mandatory sections are patient demographics and GP practice.
  - All other sections are required because if the information is there it expected to be part of the record.
  - At element level some items are mandatory all others are required

Does this approach make sense, or should some items be optional if they were optional in other standards, e.g. in the medications and medical devices section?

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## Specific Questions

6. Does “plans and requested actions” make sense as a separate section when not linked to a clinical summary or a discharge summary (for example) – is there sufficient context, if not how should we demonstrate context?
  - Does “plans and requested actions” overlap with investigations requested – should we include investigations requested underneath plans and requested actions?
7. In encounters - discharge, attendance, admission – is sufficient information included, for example does clinical summary need to be included with discharge?
8. Is there a need to record an assessment of a carer’s competence – this came up in the workshop. If so, could this be recorded under assessments?
9. Should we record if a person is interested in taking part in a clinical trial – this came up in a webinar?
10. Correspondence has been raised as a requirement. There is currently no metadata standard to support correspondence. This was highlighted as a gap in the discovery work. What metadata should be captured about a piece of correspondence?
11. Should we include a distribution list for letters?
12. We have replaced the immunisations section with vaccinations – do we need to add the following elements to cover self-reported vaccinations:
  - Reported date: The date or partial date that the reported vaccination was given in the opinion of the person and/or parent/carer
  - Primary source: An indication that the content of the record is based on information from the person who administered the vaccine. This reflects the context under which the data was originally recorded.
  - Report origin: The source of the data when the report of the vaccination event is not based on information from the person who administered the vaccine.
13. The core information standard does not include a heading for maternal medical conditions or infectious diseases arising in pregnancy which may have an impact on the foetus – would this be relevant to include? Outside of the neonatal period it may not be required. This query came up in the maternity webinar.
14. What is normal for a patient was discussed in two contexts – in relation to observations and in relation to their general wellbeing.
  - Observations are already recorded under examination findings. Is it useful to record what is normal, e.g. able to use stairs etc in the core information – where should this be recorded?



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15. One of the issues raised has been about some terms having a specific meaning with health or social care with potentially different definitions for the same term. Do any of the section or element names fall into this category?

16. The following came up in the workshop – do we want to include these?

- A record of birth parents
- Status of relationships, e.g. with father
- History of relationships, e.g. when did people become foster parents?

17. Should we record reasonable adjustments (this has been raised in relation to social care and mental health)?

### **Questions related to specific sections**

#### Patient demographics

18. Do we need to be able to capture a temporary residence, e.g. if someone is temporarily in a nursing home? Relates to end of life wishes about where someone wants to die.

19. Should we add patient activation status?

#### Personal contacts

20. Should we add in a comments field so that information about why a personal contact is important can be recorded?

#### Problems and issues and diagnosis

21. Problems and issues and diagnoses are currently separate sections – do we need both sections in the standard?

#### Disabilities section – potential new section

22. Is a section for disability required to support the recording and sharing of disability information, e.g. learning difficulties (this was raised by social care and mental health professionals) or would this be covered in either individual requirements (mobility and cognitive needs) or through problems/issues & diagnoses?

23. There is a requirement to support reasonable adjustments – is this a flag or is more information required?

#### Pregnancy status – new section

24. Does this section support the requirement to flag whether someone is pregnant?

25. Is the section name correct – pregnancy status – or should it be called something else?

#### Social Context

26. Do we need to include primary support reason (from social care systems)?

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27. Does equipment provided to the service user, e.g. wheel chair ramp need to be recorded? Where should it be recorded? Could it be recorded under devices or under services and care (in social context)?
  28. Is the services and care element within social context sufficient for recording the social care services a person receives?
  29. We will incorporate the new standards developed in Birmingham which uses AUDIT C for alcohol intake – this standard has been previously approved and is likely to be adopted by the PRSB. Is there an equivalent assessment for drug use?

#### Assessment scales (changed to assessments)

30. We have added in the following elements to capture output from social care and mental health:
  - a. An assessment element to capture narrative assessments (for social care and mental health)
  - b. Assessment summary to capture a summary of an assessment
  - c. Formulation to provide a diagnostic summary of mental health assessments

Do we also need to include an element for assessment type?

31. Would the Frailty Index: electronic Frailty Index (eFI) used by GP / Clinical Frailty Score used by clinicians be covered by assessment scales?

#### Future Appointments

32. Does this allow the capture of social care appointments (e.g. someone visiting the person to provide domiciliary care or to undertake a care needs assessment)?

#### **Questions from the second expert review group meeting (16 May 2019)**

1. Retaining clinical context of the information has been raised as a clinical safety risk. The core information standard uses the following:
  - Performing professional (the professional linked to the record entry)
  - Date (the date of the activity day/month/year, e.g. the date that the procedure took place)
  - Location (the organisation/institution at which the activity took place, e.g. the hospital at which the procedure took place)

We have reviewed this section by section and have used “performing professional” to mean different things in different sections. In some sections we have also added person completing the record where the performing professional may be different from the person that recorded the information. Does this approach make sense?

2. An additional concern raised, related to question three above, is that the information model does not articulate the links between the different types of information. For example, a diagnosis would be linked to an encounter/consultation and a diagnosis may be linked to an investigation result or an assessment. We are proposing that in

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the information guidance we include reference to the fact that all links between information need to be retained and that this is addressed in the logical data model work.

3. The principles we have used to define whether a section, cluster or element is mandatory, required or optional are as follows:
  - Minimise the number of mandatory data items.
  - The only mandatory sections are patient demographics and GP practice.
  - All other sections are required because if the information is there it expected to be part of the record.
  - At element level some items are mandatory all others are required.

We have now implemented this approach in the model and reviewed changes to MRO inherited from existing standards with clinical advisors. Do you support this approach in release one?

4. We have recognised the need to review descriptions and, in some instances, amend the description used in the standard the element was taken from. An example being we have amended the use of patient to person. Are you happy with this approach?
5. The last expert group review recognised a tension between generic and specific sections in the information model, an example being the discussion on information contained in the pregnancy section and the recognition pregnancy was a condition. We have however left the pregnancy section in the model as an exception to the generic approach as due date is not covered elsewhere in the information standard. Are you happy with this exception?
6. We have removed the history section from the information model on the basis that medical and mental health history would be included in problem lists, surgical history would be included in procedures. We are unclear however whether obstetric history, e.g. history of stillbirth and whether the pregnancy outcome resulted in a live birth would be recorded in “problem lists”?
7. We have been made aware of a specific concern about merging diagnosis and problems and issues into a single section - problem lists – which was the approach taken for the maternity record. What are your views on this?
8. We are not proposing a separate disabilities section because we believe that information contained in the generic problem list section should accommodate disabilities information. Support for people with disabilities would be included in the individual requirements section – would this section cover reasonable adjustments? Are you happy with this approach?
9. We have removed the developmental skills section because we believe that information would be covered under observations. Are you happy with this approach?
10. We have removed the person expectations, concerns and wishes section as we believe the information contained in it is duplicated in the ‘about me’ section of the Core Information Standard. Are you happy with this approach?
11. We have retained a correspondence section and plan to include metadata based on the OneLondon definition of correspondence metadata. We propose to take a similar approach to documents and images/scans. These sections are ‘catch alls’ for where

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correspondence, documents and images are not specifically referenced in other sections. Are you happy with this approach?

12. We are assuming that results of genetic testing could be supported by the investigation results section. Is that correct?
13. There have been many queries about what consent needs to be captured for sharing information but also other types of consent. We have three types of consent defined in the core information standard (as below). Are these required in the core information standard?
  - Consent for information sharing
  - Consent relating to a child
  - Consent for treatment
14. Plans are included in a number of places in the model. Are all these sections required? Where would birth plans, EoL plans, MH crisis care plans be covered?:
  - Plans and requested actions
  - Care and support plans
  - Contingency plans
  - Additional supporting plans.

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## 23 Appendix N supplier webinar questions

1. Is the scope of the PRSB's work on the core information standard clear?
2. Does the scope of the core information standard seem over ambitious?
3. Are the outputs of the PRSB's work clear?
4. Is the expectation about the issues that will be addressed locally reasonable?
5. Do suppliers support the design principles and the approach to developing the standard, including the consultation process?
6. Are there other information 'artefacts' that suppliers would like to see developed centrally?
7. Are suppliers happy with the structure of the information model, MRO and value sets?
8. What are supplier views on the areas for further work:
  - Retaining context of the information
  - Sharing documents and images

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## 24 Appendix O supplier webinar attendees

Organisation	Name
Allscripts Healthcare (IT)	Paula Cross
ATOS	Elaine Bennett
Cerner	Ben McAlister
Cerner	Oezcitak Ertugrul
DXC Technology	Nilesh Jain
DXC Technology	Derek Fleming
Graphnet	Colin Innes
Graphnet	Dawn Boswell-Challand
Kainos software	Alastair Allen
Kainos software	Graham Lyttle
NHS Arden and Greater East Midlands CSU	Pavani Yatham
NHS Digital	Michael Bond
NHS Digital	Zac Whitewood-Moores
NHS England	Catherine Leggett
NHS South, Central and West CSU	Shauna McMahon
Orion Health	Bally Toor
PA Consulting	Jeremy Thorp
PA Consulting	Proteus Duxbury
Philips UK & Ireland	Dennis Polling
PRSB Clinical Advisor	Philip Scott
PRSB Patient lead	Laura Fulcher
NHS South, Central and West CSU	John O'Connell
NHS South, Central and West CSU	Mike Mcmillan
NHS South, Central and West CSU	Catherine Dampney
NHS South, Central and West CSU	Kate Toomey
Tech UK	Michael Thick
The HCI Group	Estelle Davies