Professional Record Standards Body

Better records for better care

Digital Social Care Information:

The development of standards to support information sharing between health and social care.

Final Report

OCTOBER 2020

Document Management

Revision History

Version	Date	Summary of Changes
1.0	21/10/20	1st version for publication
1.1	27/01/20	Updated following feedback from the Royal College of Nursing
1.2	07/01/22	Updated to fix errors in the Executive summary on the five areas of focus where information was missing

Reviewers

This document must be reviewed by the following people:

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This document must be approved by the following people:

Name	Title	Date	Version
Project Board	Project Board	28/9/20	0.5
Assurance Committee	Assurance Committee	28/9/20	0.5

Glossary of terms

Term / Abbreviation	What it stands for
ADW	Assessment Discharge and Withdrawal
API	Application Programming Interface
BNSSG	(Bristol, North Somerset and South Gloucestershire CCG
CASPA	Care Software Providers Alliance
CCG	Clinical Commissioning Group
CIS	Core Information Standard
COVID - 19	Corona virus disease – 2019
CPR	Cardiopulmonary resuscitation
CSG	The NHS Digital Clinical Safety Group
CSMS	Clinical Safety Management System
CQC	Care Quality Commission
ED	Emergency Department
EHCH	Enhanced Health in Care Homes
EHR	Electronic Health Record
EoL	End of Life
FHIR	Fast Healthcare Interoperability Resources
GDPR	General Data Protection Regulation
GP	General Practitioner
HCAs	Health Care Assistants
HCPs	Health Care Professionals
ICS	Integrated Care Systems
IT	Information Technology
LTC	Long Term Conditions

LHCR	Local Health and Care Record
MAR	Medicine Administration Record
MCA	Mental Capacity Assessment
MS	Microsoft®
NCF	National Care Forum
NEWS2	National Early Warning Score 2
NHS	National Health Service
NHS CHC	NHS Continuing Healthcare
NHSD	NHS Digital
NHSX	NHS 'User Experience' UK Government Unit
NICE	National Institute for Health and Care Excellence
OT	Occupational Therapist
PRSB	Professional Record Standards Body
RBAC	Role Based Access Control
SCIE	Social Care Institute for Excellence
SCR	Summary Care Record
SNOMED – CT	Systematized Nomenclature of Medicine - Clinical Terms
STPs	Sustainability and Transformation Partnerships

Planned Review Date and Route for User Feedback

The next maintenance review of this document is planned for October 2023, subject to agreement with NHS Digital as the commissioning body.

Please direct any comments or enquiries related to the project report and implementation of the standards to support@theprsb.org.

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1. Executive Summary

The Adult Social Care sector in England is vast. It employs 1.52 million people[1] across 18,200 organisations and contributes £40.5bn to the economy.[2] Nearly four in five jobs in adult social care are in the independent sector, with local authorities, the NHS and directly employed paid carers making up the rest. Care workers account for nearly 1 million of the people employed in the sector with many thousands of registered nurses, occupational therapists and social workers.

As people live longer and with more and increasingly complex needs, so requests for social care support are increasing – up 100,000 to 1.9 million in the four years to 2018/19.[3] At the same time, people are moving between health and social care services and there is a need to ensure that health and social information about an individual is complete, up-to-date and available to professionals and staff across health and social care when needed so that high quality person-centred care and support can be provided.

The NHS Plan[4] (2019) set out the digital plan for the NHS which included greater use of electronic systems and shared care records to support person-centred care and ensure clinicians have access to the information they need to provide high quality care in health services. But this is just one half of the story. Staff working in social care – in local authorities, in care homes, in the community or providing care in people's homes – need information about the person when they are no longer an NHS inpatient (e.g. the medications they need to take) so that they can provide on-going care and support and inform clinicians of a person's change in circumstances should they need to go into hospital. The plan sets out 'guaranteed NHS support to people living in care homes because they are not having their needs assessed as well as they could be, often resulting in unnecessary, unplanned and avoidable admissions to hospital and sub-optimal medication regimes'. This will be through the Enhanced Health in Care Homes (EHCH) model and support for easier, secure, sharing of information between care homes and NHS staff.

This project supports NHS Digital's Social Care Pathfinder programme, which has funded 16 commissioners and providers of adult social care to deliver products to support wide-spread adoption of innovation and technology across the social care sector, by identifying and developing national information standards to support information sharing between health and social care, which the pathfinders can then implement and test in practice.

The project has explored five areas of focus:

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[1] https://www.skillsforcare.org.uk/adult-social-care-workforce-data/Workforce-intelligence/publications/national-information/The-size-and-structure-of-the-adult-social-care-sector-and-workforce-in-England.aspx

[2] https://www.skillsforcare.org.uk/adult-social-care-workforce-data/Workforce-intelligence/documents/State-of-the-adult-social-care-sector/State-of-Report-2019.pdf

[3] https://www.kingsfund.org.uk/audio-video/key-facts-figures-adult-social-care#:~:text=The%20number%20of%20people%20who,of%20100%2C000%20since%202015%2F16.

[4] https://www.longtermplan.nhs.uk/

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- About Me (what people who use services and their carers think is important to share with those who care for them)
- Transferring a care home resident to hospital in urgent circumstances
- Hospital referral for assessment for community care and support, where the person will need additional care when they are discharged
- Information Local Authorities can provide to enhance shared care records
- The view of shared care records which should be available to staff in care homes of their residents

The consultation followed a rigorous approach:
- an evidence review and mapping of existing data sets in use
- a mixed media consultation involving video, audio, interviews and written submissions on About Me
- four webinars attended by a wide range of multi-disciplinary professionals and people who use services and their carers
- a webinar for vendors
- two online surveys to obtain a broader group of views

It was supported by a team of five professional and lay advisors representing care homes, secondary care, social work, primary care and people who use services and their carers.

The consultation resulted in two new transfer of care standards: Hospital Referral for Assessment for Community Care and Support and Urgent Referral from Care Home to Hospital; a standard to share local authority information with a shared health and care record; and changes to version 1.0 of the Core Information Standard (CIS) to accommodate a revised section for About Me and to enable the recording of information from Local Authorities about an individual, for example regarding equipment issued and assessments undertaken. In addition, guidance about what information from a shared health and care record care home staff need access to was produced.

The following key findings arose:

There was strong, broad support that proportionate About Me information will support the delivery of person-centred care by enabling individuals to share what is important to them with health and care professionals. However, concerns were raised about information in About Me not being consistent with other information in the electronic record and the information not being acted upon by professionals. This will require a culture and process change for clinicians and professionals.

It was found that the use of multi-media for sharing About Me information would undoubtedly help people with communication difficulties and provide baseline information to professionals. However, concerns were raised about confidentiality, storage, ability to access multi-media through existing systems, time to view and lack of connectivity limiting accessibility. These concerns should not prevent the use of multi-media file sharing as people are interacting increasingly using video and audio communications but are considerations for implementation.

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Professionals identified a significant amount of essential information that would be required in the two transfer of care standards. It is expected that much of the information would eventually be provided by enabling access to a shared health and care record (e.g. for medications, allergies and past medical history) rather than transferring it when the resident is taken to hospital. Access to shared records would enable such information to be provided from source e.g. the GP's record. Some information, however, would need to be transferred at the time the resident is taken to hospital (e.g. the reason they are being transferred and any recent information about their health). The national drive to implement local health and care records will help to remove some of the burden on care home staff in providing this information and avoid delay when the resident is taken to hospital.

In addition, care homes differ widely in their digital maturity with a large number still paper-based. The burden on care home staff may increase if they attempt to send all the information set out in the Urgent referral from Care Home to Hospital standard (regardless of whether much of the paperwork is pre-prepared). The existing 'Red Bag' process (on which this standard is based) currently requires a large amount of paper information (much of which is pre-printed) and findings from a previous evaluation[5] of the 'Red Bag' was that the physical documentation often gets lost, during the transfer of the patient, it can be incomplete and it can be time consuming to generate. It recommended better use of IT in the process and this standard is an enabler for achieving that objective, however its implementation must be concurrent with a drive to increase digital maturity across care homes. Also, in order for care home staff to have access to health and social care information held in shared records the organisation needs to be compliant with the expected standard for health and social care to hold, process or share personal data[6].

The consultation on what information care home staff should have access to from a shared record concluded that in principle all staff caring for the person should be able to access the information needed (rather than some staff only having access to a subset of the information depending on their role) because of the clinical risk of having access to partial information, and it should be the responsibility of the care home 'manager' (nominated individual responsible for services as defined by the CQC) to provide and restrict access via appropriate role-based access control (RBAC) mechanisms.

The consultation on what information Local Authorities should contribute to a shared health and care record confirmed the requirements and that the standard should be both an enhancement to the existing Core Information Standard and a standard in its own right to encourage contributions from the Local Authorities.

Health and care professionals need to know that vital information about end of life wishes and preferences exists, such as an Advance Statement, an Advance Decision to Refuse Treatment,

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[5] Graham, Yitka & Keith, Sarah & Freeman, Maria & Haggerty, Ken & Dimmock, Kathryn & Hayes, Catherine. (2019). Red Bag scheme evaluation—hospital transfer pathways and their relevance to HCAs. British Journal of Healthcare Assistants. 13. 401-405. 10.12968/

[6] The Department of Health and Social Care recommend that all social care providers complete the data security and protection toolkit (https://www.dsptoolkit.nhs.uk/)

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Do Not Attempt CPR and Lasting Power of Attorney for Health and Welfare, and that it is up-to-date. This information can have an incredibly positive effect on the quality of a person's death. Concerns were raised about how this information can be made available to health and care professionals so that they can easily locate and be confident of the provenance of the information.

In August 2020, the Department of Health and Social Care issued revised policy on the hospital discharge process developed in response to COVID-19. Acute hospitals are required to discharge patients as soon as it is clinically safe to do so. Social care needs assessments and NHS Continuing Healthcare (NHS CHC) assessments of eligibility will mostly be made in a community setting and not take place during the acute hospital inpatient stay. This means that the context of the "Hospital Referral for Assessment for Community Care and Support" has changed as the assessment for support now takes place after discharge in the majority of cases. The information defined in the standard will still be required to assess the care and support needs of an individual after discharge, however it may be that it will not be transferred by the hospital to the Local Authority. This reinforces the need to move to shared records where much of the information needed could more easily be made accessible to professionals within multi-disciplinary teams from multiple organisations at the same time.

Although the NHS plan sets out that it will "mandate and rigorously enforce technology standards to ensure data is interoperable and accessible" this will also be required within social care. However, a recent study[7] found that local authorities prefer local standards to nationally mandated standards. In addition, as the majority of providers are independent sector and non-statutory providers (e.g. charities) different levers and incentives will be required to drive the implementation of standards for information sharing in these sectors.

The recommendations are:

- Pilot the new and revised standards with the pathfinders to:
  - test the processes associated with individuals creating and updating an About Me (using multi-media where appropriate) among different population groups
  - test the transfer of care standards with care homes (of mixed digital maturity) in local areas with and without shared health and care records to identify any changes that need to be made to support different environments.

- Develop and test guidance and processes for professionals using information in an About Me and undertake a wide-spread engagement programme with professionals on the About Me to drive a culture and process change.

- Continue to work with software suppliers through networks and associations such as the Care Software Providers Association (CASPA) to ensure that the digital systems comply with the standards (potential to accredit systems). When care providers purchase new digital systems, they should ensure that systems are compliant with the standards.

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[7] https://www.local.gov.uk/local-government-social-care-data-standards-and-interoperability

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- Commission technical FHIR (Fast Healthcare Interoperability Resources) messages specifications and create logical data models for the new elements, to ensure a complete set of materials to support implementation.

- Continue to work with care providers to improve levels of digital maturity supporting them to achieve the standards set out in the data security and protection toolkit (including information governance and training of staff) and the implementation of standards-compliant digital systems.

- Continue to drive the implementation of shared health and care records across ICSs and STPs.

- Conduct work on the sharing of legal and end of life information such as power of attorney, advance decisions and Do Not Attempt CPR notices to develop proposals for how the latest clinically and legally binding decisions could be shared in an electronic format (these documents are currently required to be written and signed).

- Elements relating to consent in the legal section of the standards require future review/ updating when anticipated new guidance around the lawful basis of data sharing is released - ideally this would involve new concepts or reference sets in the National Release of SNOMED CT to supplement those already existing.

- Conduct a review of what is classified as a medical device and what is classified as equipment or an adaptation in the standards is required. The current standards use the Medicines and Healthcare products Regulatory Agency (MHRA) definition (to which the NHS data dictionary is also aligned) of a medical device which includes items "for the purpose of… compensation for an injury or handicap" for example spectacles, hearing aids, wheelchairs and walking sticks. However, this requires future review updating following preliminary feedback from clinicians on where they would expect to find a record of such items.

The joining up of health and social care is continuing at pace. Around half of England is now covered by ICSs[8] which involve greater collaboration between NHS organisations, local councils and others to deliver better joined-up person-centred care and support. Joined-up working must be underpinned by shared information and these new information standards contribute to that goal. There is an opportunity now to work with the pathfinders and systems' suppliers to test and refine the standards and then rollout more widely to support the national aims for ICSs and shared health and care records.

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[8] https://www.england.nhs.uk/integratedcare/integrated-care-systems/

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2. Introduction

2.1. Background and context

NHS Digital's social care programme focuses on improving digital maturity in the adult social care provider sector (such as domiciliary care and care homes) and helping adult social care to join up its IT systems with the health sector and Local Authorities.

As part of the NHS Digital Transformation Portfolio, it has invested in 16 organisations ([digital pathfinders](#)) that provide and commission social care services, including 13 local authorities, two national charities and the National Care Forum (NCF) to enable services and products that have been tested locally to be rolled out more widely. The work focuses on standardising and sharing information between health and social care organisations. The aim is aligned with the Secretary of State for Health and Social Care's vision for interoperability and openness, open standards and appropriate infrastructure and will support local areas to improve information sharing across services, ensuring people avoid hospital unless absolutely necessary and live independently for longer.

All health and adult social care organisations must, by law (the Health and Social Care (Safety and Quality) Act 2015) share information with each other about persons they are caring for directly, to improve the care provided.[9] Information and technical messaging standards are required to share information between systems.

Information standards set out the structure and content of the information that is needed to support a particular scenario. Information standards are then developed into technical standards e.g. FHIR profiles to enable systems to share information. Some national information standards have already been developed to support information sharing between health and social care but there is more work to be done, as recognised in the PRSB report following the development of the Core Information Standard (to support NHS England's Local Health and Care Record programme[10]). This includes sharing social care information (both from local authorities and care providers) with health professionals as well as health care information with social care professionals.[11] Although the development of the Core Information Standard involved consultation with social care professionals, it was recognised that further work was required.

Working with the pathfinders to identify new (or changes to) existing standards based on their local work presented the PRSB with an ideal opportunity to enhance the Core Information Standard and to develop the portfolio of information standards to support sharing of information between health and social care.

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[9] https://digital.nhs.uk/data-and-information/looking-after-information/data-security-and-information-governance/information-governance-alliance-iga/information-governance-resources/information-sharing-resources

[10] https://www.england.nhs.uk/publication/local-health-and-care-record-exemplars/

[11] https://theprsb.org/wp-content/uploads/2019/09/Core-Information-Standard-Final-Report-1.1.pdf

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The pathfinders' products vary according to the issue being addressed. However common themes are:

- standard information sent from social care about a person into a healthcare setting at admission
- viewing of a standardised set of social care information by healthcare providers
- viewing of a standardised set of core health information by social care
- location finder – healthcare providers identifying a person's responsible local authority
- alerts to notify social care where a person is in the health system
- single referral and discharge from hospital
- use of data for prevention via the use of advanced predictive analytics
- use of artificial intelligence, assistive or remote technology

PRSB was asked to work with the pathfinders to identify up to five topic areas that could result in new (or changes to existing) national information sharing standards and conduct a national consultation to obtain consensus on standards (or outputs) for the areas of focus.

3. Methodology and consultation approach

3.1. Project objectives and scope

The overall objective of NHS Digital's pathfinder programme is to accelerate improvements in digital social care (including integration between health and social care) through the adoption of products developed locally by the pathfinders and rolled out nationally.

The objectives of this project were:

- to provide support for the pathfinders whose deliverables include developing nationally agreed standards to deliver a national consultation and endorsement, by relevant professional and patient bodies, of the standards
- to build on the work already undertaken by the pathfinders: to research published literature (including NICE guidelines) and other local projects for the same areas of focus (e.g. within the Local Health and Care Record programmes); and to analyse and further develop the standards the pathfinders have produced
- to ensure that new national standards are aligned with existing national standards.
- to obtain buy-in and support for the new national standards from professional bodies and patient organisations at a national level
- to communicate and promote the adoption of the new national standards

In scope:

The scope of the project was defined following phase 1 – the identification and agreement of the five areas of focus. This is set out in section 2.3 below.

Out of scope:

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Development of (or changes to) supporting technical messages (FHIR profiles or APIs) where they do not already exist. This will be commissioned separately by NHS Digital as required and should include assurance through PRSB by clinical and professional informaticians.

User interface definition for digital systems.

3.2. Project Governance and Resources

Project board members are set out in Appendix A.
Professional and lay advisors are set out in Appendix B.
Project team is set out in Appendix C.

3.3. Consultation approach

The project was carried out in four phases:
- Identification and agreement of the five areas of focus for the work
- National consultation on the standards with multi-disciplinary professionals and staff across different settings within health and social care and people using services
- Development and finalisation of the standards and supporting materials and final draft publication (prior to endorsement)
- Endorsement by professional and patient bodies and final publication (to follow)

3.3.1. Phase 1: Identification and agreement of the five areas of focus

The approach to this phase was as follows:
- Early discussions with pathfinders to determine approaches for developing national standards enabled the identification of areas of commonality and potential standards for development.
- Following contract award on 11th February 2020, webinars were scheduled with pathfinders to discuss the candidate areas of focus and identify any additional areas for consideration.
- Preliminary mapping between local data set specifications and existing national standards to understand level of similarity.
- A second webinar took place on 12th March 2020 to finalise the five areas of focus and approach to consultation.
- The 5 proposed areas of focus and consultation approach were ratified by the social care programme board on 17th March 2020.

The following principles were agreed in providing support for the development of national standards:
- Much work has already been achieved locally, this is not about re-doing that but building on it and gaining national consensus.
- There are already existing nationally agreed standards that cover a lot of the content – existing standards will be reused where possible.

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- Consultation activities will be consolidated where possible for the different areas of focus as it is likely that the similar stakeholders will be involved.

The following five areas of focus were agreed with the pathfinders and ratified by the Social Care Programme Board:

Areas of focus	Description	Rationale for developing a standard
About Me	- Information a person thinks important to share with carers/professionals - "Generic" About Me for all population groups including people with learning difficulties, the elderly, people with mental health conditions, pregnant women etc. - To support multi-media formats of information	- Wide range of existing care 'passports', and similar communication tools e.g. 'This Is Me', 'All About Me', etc. - Majority are currently paper-based and are held and transported by the individual and their carers e.g. unpaid relative/friend or parent if a child and sometimes as part of the Sutton Red Bag (or equivalent) if the individual is resident in a care home. - Work taking place on About Me across the country e.g. pathfinders, Local Health and Care Record programmes - Links with other national programmes e.g. Summary Care Record (SCR) and reasonable adjustments; the national record locator service and NHS England's personalised care team - Recent work on Core Information Standard identified that further work was needed on About Me and it would be timely to undertake it now given current activity in this area
Care Homes View (of Shared Health and Care Records)	- Health and social care information needed by care home staff - For any type of care home (residential or nursing)	- Definition of "views" of the Core Information Standard for different users was identified as further work needed as it was always envisaged that professionals with different roles, in different situations, (e.g. an A&E consultant, a GP, a Nurse, a Midwife, an allied

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		- health professional) and people themselves accessing their own records would require access to different subsets of the information
		- Bristol, North Somerset and South Gloucestershire (BNSSG) has developed a data set from their local health and care record – Connecting Care – (based on broad local consultation) to be used within care homes. This is considered one of the most digitally mature solutions for care homes and developing this into national guidance for care homes will assist others.
		- Providing care home staff with access to up-to-date information will provide them with more confidence in decision-making, reducing referrals to Emergency Departments and General Practice and support them to make assessments before discharge to facilitate medically fit discharges and reduce length of stay in hospital.
		- As there are differing levels of digital maturity across care homes, but a current drive to increase maturity, this work would be timely.
Local Authority Information (for Shared Health and Care Records)	- Information recorded by the local authorities such as assessments, care packages, equipment and referrals etc. and shared with health professionals and other social care professionals via shared records.	- Nottinghamshire County Council has existing standards in use for sharing information from social care to health partners and are sharing their work with three LHCR communities. - It was recognised that more work needed to be done with social care partners to further develop the Core Information Standard to support sharing of social care information and basing the information

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		requirements on the work of Nottinghamshire that will potentially be used widely would be a good basis for gaining national consensus.
Hospital Referral for Assessment for Community Care and Support	• For patients discharged on pathways 1 – 3 where additional support or care is required following discharge • Covers referral process and Assessment, Discharge and Withdrawal standards • For any type of additional support and care needs e.g. domiciliary care, residential care, step down care	• This 'Single Referral' information should provide the information to enable the clinically correct discharge pathways for patients with complex needs to be selected and to communicate key information about the patients' recent stay in hospital and their ongoing care needs to community providers in physical and mental health and in social care. Bristol, North Somerset and South Gloucestershire (BNSSG) are implementing a bureau to support the most complex and vulnerable patients in the system – those that require enhanced support in community to reach a new baseline of fitness after a hospital stay. The aims of the bureau are to reduce the time taken to discharge the patient after they have been declared medically fit and having the right information will help this. Delayed transfers of care are a major problem in the system and therefore developing a national standard based on the work of Bristol, North Somerset and South Gloucestershire and other pathfinders addressing similar problems including Nottingham County Council who are sharing referral and Assessment Discharge and Withdrawal information with local authorities should help to address this. • The existing ADW standard could be considered as part of the same scenario and other pathfinders are currently implementing this standard. This work has identified a number of changes to the existing standard and therefore national consultation on these

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		changes is proposed in conjunction with the work on the single referral form to obtain consensus for the changes.
		• As the ADW standard is currently being implemented by a number of pathfinders and there is feedback on the standard, it would be appropriate to review this in conjunction with the single referral information requirements to determine what information should be part of the ADW standard and what should be part of a referral standard as although they can be used in conjunction, ADW can also be used separately.
Urgent Referral from Care Home to Hospital	• based on the information shared in the Sutton Red Bag and other equivalent schemes • covering any type of care home including residential and nursing homes	• The Red Bag (or Hospital Transfer Pathway) initiative has been in use for many years. As part of the pathfinder programme Sutton are creating a digital Red Bag to send the information (traditionally included as 12 paper forms directly to the hospital receiving the patient). • Bristol, North Somerset and South Gloucestershire is also implementing the Red Bag however following consultation they are looking to amend and rationalise some of the information captured and shared (in particular the About Me information). • It would be timely to bring together the findings of Sutton, Bristol, North Somerset and South Gloucestershire and other pathfinders into an information standard to support this scenario and consult nationally so that others can use this standard more widely.

The pathfinders are focusing on the following areas:

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Organisation	Hospital Referral for Assessment for Community Care and Support	Care Homes View (of Shared Health and Care Records)	About Me	Urgent Referral from Care Home to Hospital	Local Authority Information (for Shared Health and Care Records)
Bristol City Council	X				
Friends of the Elderly		X			
Hf Trust			X		
Lancashire County Council	X				
Leicestershire County Council		X			
London Borough of Bexley					
London Borough of Islington			X		
Manchester City Council	X				
National care forum					
Nottinghamshire County Council	X		X		X
South Gloucestershire Council		X	X	X	
Sutton Council			X	X	
Westminster City Council		X			
Wirral Council	X				
Wolverhampton City Council					
Worcestershire County Council					

3.3.2. Phase 2: National consultation

The PRSB approach to the development of the standards was as follows:

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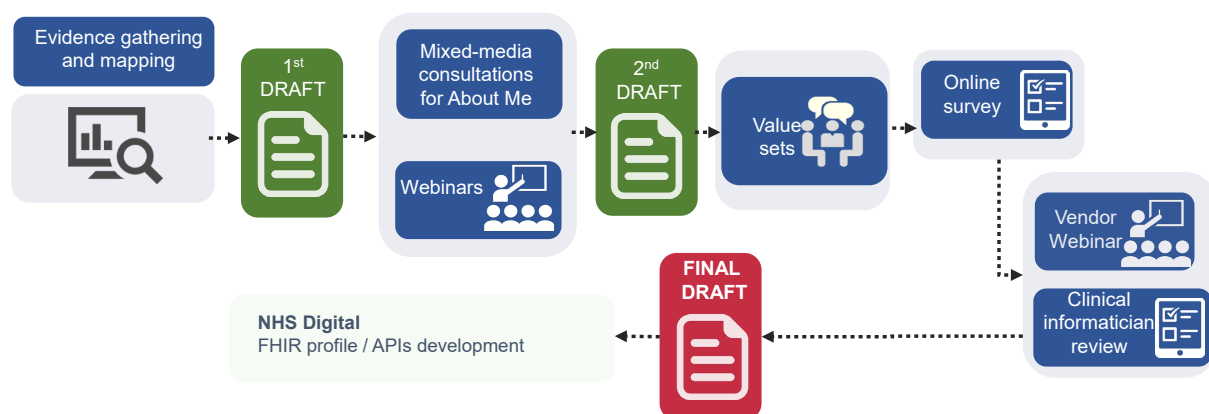
- Evidence review and mapping (of local data sets/standards to existing standards) to develop first drafts
- Multi-media consultation with people who use services and their carers on the information that they would want to share in an About Me (some professionals also contributed videos at this stage).
- Work with NHS Digital terminologists to assign value sets to the data elements in the standards where appropriate.
- Four webinars with multi-disciplinary and citizen representations to result in a second draft
- Two online surveys to a broader group of stakeholders to result in a final draft
- Vendor webinar and consultation with clinical informaticians to finalise the standards and raise awareness for support and implementation
- A Clinical Safety Case was conducted in parallel with the national consultation

Evidence review and mapping

The approach to the evidence review and mapping for each of the five areas of focus was as follows:

- Evidence review: The purpose of the evidence review was to identify literature that might inform and justify the selected Digital Social Care Information products. The scope was necessarily limited to a narrow key word search utilising the Social Care Institute for Excellence (SCIE) database to identify relevant articles (e.g. Local Government Association etc.) and guidance (e.g. NICE), standards and research. Citation chaining was then done on these where practical to identify further resources. The terms used in the key word search were identified in documents provided by the Digital Social Care Pathfinders, such as project initiation documents and final reports. Some resources were also identified using the Google Search engine.

- Identifying and mapping existing examples of paper forms (e.g. care passports and Red Bag documentation) and digital models related to the five areas of focus to the PRSB standards and each other to identify areas of commonality and differences to be addressed during the consultation.

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About Me

Two key papers were identified:

- Prodinger *et al*[12] consulted patients with chronic conditions to identify 16 subject areas (or headings) that they felt were most relevant for Electronic Health Records (EHR) these covered medical and personal aspects such as emotions, motivation, sleep and memory or thoughts, mobility, social activities, finances, understanding of health issues and treatment or care priorities and goals.

- Northway et al[13] reviewed 60 care passports from across the UK for commonality. They identified considerable variation with the way the data was structured but identified common themes such as communication and support needs.

The findings (headings) from Prodinger *et al.* and Northway *et al.* were mapped against the PRSB standards[14] to identify frequency of occurrence, similar sections and overlaps as well as differences. These were mapped alongside:
- Care Hospital 'Passports' comparison spreadsheet (received from NHS Digital, work was undertaken in 2017)
- Who Am I (used by Sutton pathfinder for digital Red Bag initiative, Person Centred Software)
- About Me (used by South Gloucestershire pathfinder, Connecting Care)
- Integrated care and support plan (used by Manchester LHCR, Graphnet)

The following common themes were identified:
- Demographics
- Important people
- Communication support
- Supporting independence - personal care, toileting, eating and drinking, mobility, taking medication, sleep, work, study and leisure
- Likes and dislikes
- Triggers and consequences of anxiety, stress and other emotions
- Reasonable adjustments and impairments
- Me on my best day (this was not identified in the mapping work but was raised in subsequent conversations)

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[12] Prodinger B, Rastall P, Kalra D, Wooldridge D, Carpenter I. Documenting Routinely What Matters to People: Standardized Headings for Health Records of Patients with Chronic Health Conditions. Appl Clin Inform. 2018;9(2):348-365. doi:10.1055/s-0038-1649488

[13] Northway, R, Rees, S, Davies, M, Williams, S. Hospital passports, patient safety and person-centred care: A review of documents currently used for people with intellectual disabilities in the UK. *J Clin Nurs.* 2017; 26: 5160– 5168. https://doi.org/10.1111/jocn.14065

[14] https://theprsb.org/standards/

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Care Homes View (of Shared Health and Care Records)

The majority of publications identified by the key word search for the Care Homes View (of Shared Health and Care Records) were considered to be out of scope. However, several documents relating to information that care home staff might record relating to residents' care needs – in particular the Minimum Data Set Resident Assessment Instrument for Long Term Care Facilities (MDS – RAI) is a tool that is widely used internationally, and may inform future work and facilitate discussion relating to standard(s) for data recording in care homes and domiciliary care.

The mapping process for the Care Homes View (of Shared Health and Care Records) was derived from an original first stage process conducted by the Digital Social Care Pathfinder, which involved the following:

- A consultation process and workshop conducted by the Pathfinder identified key information that was needed by care homes. If you require further information about the project deliverables, contact the PRSB via support@theprsb.org or Tel: 02079227976
- The identified requirements were then mapped to the PRSB Core Information Standard (CIS) to produce a minimum care home dataset. This dataset is available to view in Appendix A of a separate document – the Care Homes View (of Shared Health and Care Records) Guidance
- A role-based access control (RBAC) proposal for the Connecting Care digital shared care record system (Bristol, North Somerset and South Gloucestershire CCG (BNSSG)) was made for use in care homes.
- The mapping process was refined to ensure that the Care homes view of the CIS was compatible with existing PRSB standards. This was done in parallel to a wider updating project for the CIS. The BNSSG RBAC proposal was also mapped to the CIS, although this derived product was not ultimately supported by the consultation process (See the Care Homes View (of Shared Health and Care Records) Guidance product).

Local Authority Information (for Shared Health and Care Records)

Key papers identified were:

- Local government social care data standards and interoperability, Sept 2019
- Safeguarding adults: sharing information, Jan 2015, updated Jan 2019, SCIE
- Nottinghamshire County Council pathfinder provided a set of FHIR profiles they had developed to share local authority information with the East Midlands Local Health and Care Record. These were mapped against the existing PRSB standards to identify new components or changes (for further consultation). The FHIR profiles can be found here: https://simplifier.net/guide/SocialCareDataService/SocialCareRecord.

Key findings from literature review and mapping:

- Councils prefer local standards as opposed to nationally mandated standards
- The literature included examples of elements based on consultation with front line

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professionals – in line with PRSB Core Information Standard
- NHS number required – but there are council issues with NHS number tracing
- Distinction between adult and children's services
- Councils want to share (in addition to the examples in the literature):
  - Information about children transitioning to adult social care
  - Deprivation of Liberty Safeguards
  - Education healthcare plans
- The mapping between the FHIR profiles and the PRSB standards (the Core Information Standard) showed good coverage as a number of areas were previously consulted on such as assessments, care packages and equipment. However, the mapping identified that these sections would likely need to be modified to fully accommodate local authority requirements.

Urgent Referral from Care Home to Hospital

Two key papers were identified evaluating the Red Bag initiative:

- Red Bag scheme evaluation—hospital transfer pathways and their relevance to HCAs by, Graham et al (2019)[15] – this used a mixed methods approach to identify areas of best practices and gaps in the Hospital Transfer Pathway
- Evaluation of the 'Red Bag' Hospital Transfer Pathway in South London, Health Innovation Network, January 2019[16] – this used a mixed methods study including survey, interviews and focus group to identify how successful the Red Bag initiative had been

Key findings from literature review:

- Where adhered to well the Red Bag pathway improves communication between paramedics, care home staff and hospital clinicians
- There is considerable variance in practice of using the Red Bag scheme (implementation, strategies, processes e.g. paperwork, what items are included, the physical bag type etc.)
- Documentation missing or incomplete
- Lost bags / information not checked by staff
- Paperwork should be simplified to reduce the time taken to fill it in
- Maximise the use of IT solutions

The 'hospital pack' developed by Sutton pathfinder and Person Centred Software in their work to digitise the Red Bag was mapped against the PRSB standards and there was significant commonality between them. Potential areas identified for further consultation were:

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[15] Graham, Yitka & Keith, Sarah & Freeman, Maria & Haggerty, Ken & Dimmock, Kathryn & Hayes, Catherine. (2019). Red Bag scheme evaluation—hospital transfer pathways and their relevance to HCAs. British Journal of Healthcare Assistants. 13. 401-405. 10.12968/

[16] https://healthinnovationnetwork.com/news/evaluation-into-red-bag-hospital-transfer-pathway/

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- nursing care
- information about challenging behaviour (behaviour support plans)
- history of falls
- hospital admissions in last 12 months
- GP consultations
- mobility, movement and handling
- list of belongings the resident was transferred to hospital with

Hospital Referral for Assessment for Community Care and Support

The following was identified from the mapping work:

- Many sections and elements already map to existing PRSB standards – areas to consult on include nursing care management and social care
- There is similarity with the Urgent Referral from Care Home to Hospital (Red Bag) and Local Authority Information standards e.g. falls history prior to admission, aids to mobility/transfer prior to admission and Occupational Therapy aids
- Need consistency between different standards e.g. Long-Term Conditions (LTC), previous medical conditions and formally diagnosed LTCs should all be mapped to the problem list section

<u>Mixed media consultation on About Me</u>

The original consultation design for this project included two regional face to face focus groups based in the North and the South of England to bring together a representative group of people who use services to discuss their views and concerns regarding what information they would want to include in an About Me section of the health and care record.

However, the COVID-19 pandemic necessitated a different approach to this given the requirement for people to stay at home (work from home) and many of the people who we wished to engage with were shielding or self-isolating. The revised approach involved asking people in care homes and individuals receiving social care at home, informal carers and/or community-based professionals to record videos or audio clips or provide written evidence responding to questions about information they would chose to include in an About Me. Hard to reach groups were also contacted and telephone interviews were undertaken in some cases.

In all, 14 people with a wide range of needs (including those with learning disabilities, physical disabilities, mental health conditions and older people resident in care homes) produced powerful testimony, identifying holistic and person-centred care, reasonable adjustments, autonomy and control as high priorities. This was supplemented by input from 22 carers, family members, therapists and support workers speaking on behalf of those they support.

The questions can be found in Appendix E and the list of contributors in Appendix F.

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Key themes from the multi-media consultation are set out below:

Themes	Description	Quotes
Holistic view of an individual	The About Me should enable the individual to provide a holistic view of themselves e.g. social, work, study, family and friends, hobbies, values, likes and dislikes and things that are important to them	"I do really like it when medical professionals try to find out the bits about me so that assumptions [about what she can and can't do] aren't made about my disability. By hearing a bit more about life outside of the hospital or outside of a medical ward then suddenly you're a person and people can see I'm not that very different from them even though my body might be a slightly different shape" **– Service user**
Maintaining independence	The About Me should enable the individual to record what they can do themselves, what they need support to do and how they like to be supported.	"I think if you are providing support to anybody with any kind of degree of impairment, it could be someone with a learning disability, it could be someone with a sensory disability or a physical disability. It could be an older person. The key thing is to give that person as much autonomy as you can. Don't think for them, don't finish their sentences, don't anticipate and make decisions on their behalf unless you have been specifically asked to do so. If in doubt just ask." **– Service user** "It's really important to break down the type of support I need and where. As well as support with everyday tasks, I need additional things to feel safe and comfortable. E.g. my phone can help to communicate. I need my glasses to read if I am going into hospital." **– Service user**
Communication	The About Me should enable the individual to record how they communicate normally and when in pain or distress, how they make informed choices and how to communicate with them	"in the context of a hospital visit or a stay at hospital or an appointment it would be important for someone caring for [him] to know that he's not very good at communicating his pain or how he is feeling or if he feels unwell he would find that quite difficult to communicate." **– Parent carer**
Reasonable Adjustments	Information should be made available to hospitals so that they can make the changes	"I was quite shocked at the number of care appointments she was unable to access due to her

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	(reasonable adjustments) needed to support an episode of care for an individual	disability [cerebral palsy]" – **Personal Assistant** "because he is limited verbally …. he uses a voice output communication aid to help him communicate his basic needs and he only understands very simple instructions … He finds new situations extremely challenging and worrying and can react negatively to something new or unfamiliar. He needs a lot of extra time so if he goes to a new appointment [in a new situation] he can't be rushed he needs much longer time to settle and adjust to the situation.." – **Parent carer**
Wellbeing	Knowing who the person is when they are well and signs that they may be becoming unwell, what helps them to maintain wellbeing. The About Me should enable the individual to record this information as well as the triggers that can cause a change in emotions and behaviours, the consequences and how can they be prevented	"If someone is very ill and in a very negative state of mind their cognitive abilities can be compromised. Knowing who they are when well is very important evidence. Mental health clinicians see people at their worst, and it is important to know what the essential human being is when they are well. This could include any positive aspects of life from photos, videos to letters from people they value, what represents them as the person they are as opposed to the patient." – **Service user** "Recognising when a person is unwell is all about what people say, do, how they appear. It can be about changes in appearance and behaviours including not changing clothes for days, not eating, behaving differently. These are often the obvious signs that someone is unwell. But there are less obvious and more subtle changes that can happen earlier during an episode of becoming unwell that are important for carers and professionals to be aware of so that they can intervene earlier" – **Service user**

Webinars

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The outputs from the evidence review, mapping work and the mixed-media consultation for About Me were developed into set of first draft information models (standards) and set of themes for consultation at a series of four webinars for people who use services, carers and health and care professionals.

Webinar 1: Local Authority Information (for Shared Health and Care Records) / Care Homes View (of Shared Health and Care Records)

Webinar 1 was held on 7th May 2020. There was a total of 78 attendees representing a wide range of health and social care disciplines as well as people who use services and their carers. 27% of the attendees were care home staff, social workers or healthcare professionals, 8% were service users or carers and 9% were from local authorities. It should be noted that a number of attendees from the pathfinders were also local authority staff or representing care providers). A list of the attendees is included in Appendix G.

High level view of the first draft of the Local Authority Information Standard is below:

Patient demographic details	Equipment
Referral details to local authority	Professional contacts
Services and care information	Personal contacts
Assessments	Personal contacts
Safeguarding concerns	Alerts

High level view of the first draft of the Care Homes View (of Shared Health and Care Records) (with original RBAC proposal) as discussed in webinar 1 is shown below:

NB: All sections to be viewed by care home 'professionals' and sections highlighted in blue to be viewed by care home 'administrators.' For further information about the development of the RBAC for care homes – see the Care Homes View (of Shared Health and Care Records) guidance document.

Person demographics	**Risks**	**Problem list**
Professional contacts	Encounters, referrals and future appointments	**Documents**
Personal contacts	Investigations, Examinations and Assessments	**Allergies**
Safeguarding	Medications and medical devices	**Individual requirements**

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Alerts	Care plans e.g. end of life, digital care and support plan	About me
Legal information		

Key themes and outputs from Webinar 1 are set out below:

Local Authority Information Standard:

Themes	Description	Quotes / Comments
Access to information	Clinician stakeholders anticipated that the information held by local authorities will be valuable diagnostic clinical reasoning and considerations for patient follow-up.	"From my perspective as a Geriatrician, real-time access to social care data can help a clinician establish a much more confident and concrete diagnoses. Evidence of changes in care and the timeframe that [this] has occurred in might help a clinician better support someone with mobility problems in developing a treatment plan or rehabilitation fund." – **Geriatrician** "When patients have been in contact with services in an emergency, as a clinician you don't often know what happens to the patient once they have been discharged. In instances when social care has this information on whether care packages have been implemented and whether the person is actually safe at home, sharing this information would be very valuable." **- GP** "Often when it comes to discharge decisions or the ability of people to receive remote monitoring solutions … there could be some simple information that local authorities may hold from previous interactions that would allow decisions to be made more quickly. Home care agencies would hold this information, but local authorities might hold this information too." **- Chief Integrated Care Officer**
Issues recording equipment	Local authorities are heterogenous in the type of data they hold regarding equipment,	"Equipment is a problematic area in terms of how it is recorded – in an OT assessment or outside of

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	which is often very limited. It should be recognised in the standard that this data may need to be collected from elsewhere. Information that could be recorded includes the reason for the equipment and type.	that – pre care act assessment. Systematic perspective – pre care act eligibility is outsourced so some of the assessment information and detail may not be held in the local authority system. So just something to consider in terms of the inconsistencies you may get in recording of types of equipment issued." **– Business Analyst** "The equipment is often a subcontracted service due to maintenance. Whole teams and departments are responsible for equipment. Perhaps a link to equipment might be better." **– Clinical Analyst** "Equipment - the reason why the person has a piece of equipment is also important to know" **– Technology Manager** "Does "equipment" include software tools, or only hardware? We often need to work with providers to ensure everyone knows a person is using My Health Guide, for example." **– Technology Manager**
Safeguarding recording issues	Sharing safeguarding information is a sensitive and safety critical challenge. In particular, information should not be shared in the record if there is a danger of accidental disclosure of a person's information to others who may be putting them at risk. See clinical safety case.	"Regarding the safeguarding element, the concern from a local authority and IG perspective is which specific parts of safeguarding are we doing and where does health particularly make a distinction between risks, alerts and safeguarding? Are we thinking about section 42 inquiries or are we talking about all types of inquiries? How do you go about publishing the outcome? What is the benefit of this information to the receiver in health? Lots of difficult questions about sharing this information." **– Business Analyst** "…within one local authority trying to decide what adult social care alerts might be and what is appropriate was difficult. For example, a suggestion of violence in a family setting and the implications of this if that

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		information is not substantiated but is shared. However, this is the most critical information that most other agencies do want to know so that's the hard bit about trying to get that battle sorted." **– Business Analyst**
Importance of recording professional contacts	Professional contacts is an essential section of the standard that may be overlooked and can help obtain further information.	"One of the overarching requirements I've come across in all the work I've done is professional contacts, which is often one of the elements which is most overlooked. If you have got professional contacts in shared care records, you have a point of contact to get or gather the rest of the information. Getting professional contacts and the circle of care in place are high-level requirements." **– Business Analyst**
Importance of contextual information	Contextual information (metadata) such as date and time of entries into the record is helpful for establishing provenance and aiding diagnosis.	"From a secondary care perspective, it is very useful to have the ability to understand the temporal nature of the interventions, when they've happened. If somebody has had a lot of professional contact in a short space of time, a lot of equipment in a short space of time or a rapid change in their service requirements over a short period of time - that's really quite helpful diagnostic information." **– Geriatrician**
Communication preferences	Communication preferences should be shared in line with the Accessible Information Standard and with health care services.	"[Regarding] communication preferences, there may be a holding places in the local health care record, but you must think about how the information gets into there. If someone is coming from social care and it is the first interaction with a hospital, the hospital is going to have to find out the communication requirements for the person. If these are already known in social care, then that needs to be made available. Having a place in the local authority record which is compatible with the local healthcare one would be important." **– GP**

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		"Sharing a person's communication preferences and needs in line with the [accessible information standard](#)." - **Digital Project Manager**
COVID – 19 considerations for discharge	Personal contacts are an essential aspect of the record standard for contact tracing during the pandemic.	"[Critical] to discharge planning for people who are COVID positive is understanding who the personal contacts are of people who are COVID positive, and if they are high risk. Especially [identifying] those who cohabit has been very important in discharge planning recently. If any of this information is available in local authorities, then it would be useful to share, and it would enable us to provide better care to people that are being discharged with COVID." **– Geriatrician**
Person environmental considerations	Social context data about the person held by the local authority should be shared in the standard.	"Environment – access, steps to the property. This is information that is recorded in social care, but often in an unstructured way. Occupational therapy assessments will hold a lot of that information. My experience in Dorset was that we used a single assessment for OTs and social care which meant that a lot of that detail was lost unfortunately, other local authorities may slot that into a specific OT assessment. Embedding the standard into local authority working practise is important, there is no real kind of standard coding behind a lot of this stuff." **– Business Analyst**
Legal information	There is significant overlap in legal requirements between health and social care and this should be reflected in the standard.	"Advance Statements can be very important in a social care setting - e.g. making it clear that a person does not want be admitted to hospital - this needs to be clear to a social care team as much as a medical team." **– Geriatrician**
Reducing burden on clients / residents / patients	Reducing the need for persons to tell their story to different professionals more than once is an important benefit of sharing local authority data in shared care records.	"As a social worker, citizens often complain they have to repeat their information when they access different health and social care services, if we can minimise this

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| | | that would be very beneficial." – **Social worker** |

Care Homes View (of Shared Health and Care Records)

Themes	Description	Quotes / Comments
Access to information for care homes (benefits)	There are many benefits of giving care homes access to health and social care data held within shared care records (see quote). It is important that the About Me section is included in the standard.	"There are lots of potential benefits of shared care records, ensuring that people don't have to tell their story more than once by making information accessible to professionals every step of the pathway, improve transfers of care by making them safer and more efficient. There are also benefits around enabling care professionals to make the right decisions at the right time based on up to date information in one place and importantly not requiring us to spend a lot of time on the phone or waiting for fax or post. Access to records can also help with increased confidence in decision making, especially in having better access to information from the GP - record as out of hours services can sometimes be hard to get hold of. Shared care records are an important part in recognizing care homes as a valued partner to the NHS and to local authorities. There are already shared care records between many different parts of health and in some areas, it is happening with the NHS and local authorities in the LHCRs and so expanding this to care homes is the next step in demonstrating the parity between health and social care." – **Digital Engagement Manager** "I think having access to about me is something that all individuals involved in care should have access to." – **Digital Project Manager**
Issues with RBAC proposal	There are challenges with the RBAC proposal including consistency with other information	"The proposals in terms of the two roles are slightly at odds with the current national thinking around

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	products. Stakeholders felt that several roles identified for limited access would be over filtered by the RBAC proposal.	the LHCR four roles, particularly around the two administrative roles and some of the things mentioned in the encounters, referrals and future appointments would potentially expand to more of a summary space. There are several areas where they cross over role aligning the two would be important going forward." **– Business Analyst**

"If we're considering support workers and carers under the care home administrator section it would be relevant for them to be able to see some of that key information like care plans as well so definitely about me because that is the information that they're following every day when they're providing support for people." **– Registered Cluster Manager**

"I think information around things like the advance statements and end of life information needs to be available to the administration as the way a home is run will often dictate what happens in particular situations which do not always align with individuals' desires." **– Geriatrician**

"I manage a large nursing home, we also support assisted living as part of it and all the staff need to be aware of what the risks are for our residents and so I think it's about identifying them as risks and sharing it with people because they need to have the information so that they can care for people correctly. They quite often have to administer and support things when the nurses aren't available. We have senior care staff as well that work in the same way as the nurses and can administer complex medication and quite rightly they have to have the correct training to do that." **– Care Home Manager** |
| **Future considerations** | Care homes also hold information, that in a future project, should be developed into | "We have always talked about the standard in terms of care home's being able to view information in |

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	a standard.	a shared care record but trying to recognize that care homes are equal partner in this and they will have information that other's won't necessarily have such as about me, care plans, documents and risks. I know there are wider implications of care homes sharing information out but there's something to consider for the future." **– Business Analyst**
Issues with the size of the standard	Stakeholders were concerned about the size of the standard being a burden on care home staff and requested a summary view. Others acknowledged that this was a challenge that was out of scope and that usability and interface issues will be resolved and defined locally (see safety case).	"The more complicated the system gets the more information that gets missed. The outcome of this needs to be very simple and easy to fill in." **– Care Home Manager** **"**Distinction in this conversation between information that you have presented to you and information that you can dip into and it strikes me that the care home will want to have a relatively brief and concise document but it may be that under certain circumstance would like the opportunity to dip into a wider array of information. The idea of a summary document something like a summary care records, if there is any way of drawing distinction between these that might be helpful." **– Geriatrician** "…the local design of how this will present on screen is in the gift of the local shared care records, they will be different…, it is often down to how they have evolved and that is that the basic of the shared care record is about getting information in to start with and a lot of that heavy duty work is about collating and getting that information together. I think the next phase of the shared care record is going to be about how do we make the design of it better so individual users and individual administrators can get the best information presented to them. As it is a collation of information within a digital system it is quite difficult to present it for everybody

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in the same way or in a perfect way and that's part of the requirements work [that] needs to be done to establish how particularly users want to see things, it's part of the work I've been doing on end of life at Wessex. ." **– Business Analyst**

"There has been lots of research in the States which has found that lots of health information that is shared isn't reviewed or looked at by professionals because it's just too unyielding so it's really important, so presentation and usability are really important." **– Clinical Analyst**

The following updates were made to the Local Authority Information (for Shared Health and Care Records) resulting from Webinar 1 (changes are highlighted in blue).

Patient demographic details	Equipment
Referral details to local authority (**Referral to added**)	Professional contacts
Services and care information (**care funding source added**)	Personal contacts
Assessments (**Structured assessments was removed**)	Personal contacts
Safeguarding concerns	Alerts
Legal information (added) (Mental capacity assessment, Mental Health Act or equivalent status, Deprivation of Liberty Safeguards)	**Primary support reason (added)**

There were a small number of changes to Care Homes View (of Shared Health and Care Records) as a result of webinar 1. These were updates to the About Me section, updates to Individual Requirements, impairments and reasonable adjustments and updates to Deprivation of Liberty Safeguards (under Legal Information).

Webinar 2: Hospital Referral for Assessment for Community Care and Support

Webinar 2 was held on 14th May 2020. There was a total of 69 attendees representing a wide range of health and social care disciplines as well as people who use services and their carers. 28% of the attendees were care home staff, social workers or healthcare professionals, 9% were service users or carers and 7% were from local authorities. It should be noted that a

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number of attendees from the pathfinders were also local authority staff or representing care providers). A list of the attendees is included in Appendix H.

A high-level overview of the components of the first draft of the standard discussed in the first webinar is below (information not previously in PRSB standards highlighted in blue):

Person demographic details	**Health, social and personal care needs summary**	Planned and requested actions (following discharge)
Referral details (from hospital) for community care and services	About me, Individual requirements, assessments, risks, alerts	Important Personal and professional contacts
Clinical and admin admission and discharge information	Legal, consent and safeguarding information	**Administrative and funding source information**
Problem list & procedures	Medication, medical devices and allergies	
Clinical summary and therapies and interventions received	Relevant documentation e.g. End of Life (e.g. ReSPECT) and behaviour support information	

Key themes and outputs from Webinar 2 are below:

Themes	Description	Quotes / Comments
Different needs for different end users and scenarios	Stakeholders emphasized that different users and situations would require the standard to include different information in order to serve distinct scenarios.	"From a Geriatricians perspective the bits of medical and healthcare data from a social care perspective are a little bit different from what a GP may want to know. For example, behavioural strategies in the nursing record need to be captured and conveyed to the social care team so they can adequately plan for someone's discharge. From a medical perspective, prognostication and the likelihood of change or recovery over time is important but is not commonly made explicit in medical discharge summaries to general practitioners. If I was planning a care package for someone in the community, I'd want to know from the doctors that had been managing that patient in hospital whether they thought that their symptoms would disappear or improve and how quickly they thought that might happen." **– Geriatrician**

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		"Most of the data is probably already covered by other information standards but it's useful to sense check the existing standards to make sure they include everything needed for discharge planning. For example, you have an admission and the discharge on the core information standard but when you're looking at discharge planning you might want to know admission reasons, estimated discharge date as well as the actual discharge date and maybe certain stages someone would go through during an admission." **– Business Analyst**
Access to information for local authorities (benefits)	Local authorities (LAs) and care homes will benefit from the information in the standard being shared from health, where currently the availability of this to LAs is limited.	"I am a social worker and I work for a London local authority. The way I envisage this standard helping and supporting me and my frontline staff is to make sure that we have the right information at the right time. The information we get from health colleagues it's very scant, what this standard would do is built upon that and ensure that all the right elements are covered so that we can make informed decisions on the required funding and ensure hospital discharge is a quicker, smoother process." **– Social Worker** "At the moment our care homes don't have access to our shared care record but that is definitely the longer-term vision, through the LHCR. There may be some additional information as part of a transfer of care where you draw their attention to specific needs and changes if they are different from on admission or there may be new into a care home." **– Business Analyst**
Implementation issues	Stakeholders identified a significant number of implementation issues. A few of which are shown here such as duplication of data, cross-boundary flow, two-way communication.	"We must not forget the cross-boundary flow in London, there are 32 or 33 local authorities in London, I think there's 10 in Manchester. You receive care where you live, not where you fall ill." **– Clinician** "I am particularly interested in how discharges submitted from a care home are expected to return there and I think because of problems with information sharing and a lack of trust sometimes between different

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		organisations that it's kept very separate, I feel this is a huge barrier that needs to be addressed. If the standards included gathering information from the care home, it would help to overcome some of these barriers." **– Nurse Prescriber** "As a social worker I am delighted this work is going on and in part this is the reason I stepped out of practise to be part of this change. My question is how we can see this actually implemented? What conversations you're having with IT suppliers that aren't specifically working with local authorities? It is important to make the distinction that the IT supplies in authorities are different from that for care providers." **– Social Worker** "I remain concerned about duplication of information being passed (and recorded) in separate systems, especially where you have shared care records. You end up feeding the shared care record the same information from multiple sources, which then needs to be managed/handled." **– Business Analyst**
COVID – 19 considerations for discharge	Stakeholders emphasised the challenges arising from the current pandemic for use of the standard.	"The parts of covid-19 that require specific consideration when discharging to social care are what sort of barrier precautions are required, how long someone requires barrier precautions, and will there be any sort of follow up testing. I would have thought these would be similar for any type of infectious disease." **– Geriatrician**
Input from personal contacts	Stakeholders repeatedly established the importance of identifying personal contact information held by the local authority e.g. collecting information from a family member for acute care.	"My perspective is that often family members are the ones that notice small changes that in hospital perhaps don't have such a big impact but on discharge they can have a really big impact and that needs to be planned for in advance. Often, I feel like we don't have the opportunity to feed into that process and that gets missed, resulting in failed discharge or increased problems." **– Service user** "As a social care professional, you are dependent upon a family member being there when you make an

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		assessment to arrive at a reasonable set of conclusions, similarly as a health care professional you have to make an assessment at the opposite end of the admission. When someone comes in from a care home, I don't need to know just how they are now, but I need to know how they are at their best and I need to know how rapidly they have changed from their best to where they are now. The information standard needs to capture that in a consistent way." **– Geriatrician**
Importance of professional contacts	Stakeholders re-emphasised the theme from webinar 1 – the importance of the inclusion of professional contacts in the standard.	"Where a person has been admitted into hospital from a care home, important professional contacts needs to include a named person in the care home who can feed into the discharge planning." **– Nurse Prescriber**
Discharge considerations	Stakeholders urged the recognition that data held in the record should include prognostic data for later use in care planning in the community.	"Important to realise that the discharge from hospital documentation should not just be a snapshot of the patients' needs at the point of discharge but also: a) the care strategies which have been used and shown to work as an inpatient, e.g. behavioural/nutritional strategies within nursing; and b) a sense of how care needs are likely to change after discharge - particularly some prognostication as to the likely rate of recovery. In current discharge paperwork to social care it is usually, particularly, medical prognostication, which is missing, and this has significant implications for care packages, planning and, indeed, were a patient is placed on discharge." **– Geriatrician**

The following changes were made as a result of webinar 2:

- Assessment Discharge and Withdrawal section
    - Assessment notice to Local Authority (added)
    - Notice receipt from Local Authority (added)
    - Discharge notice to Local Authority (added)
    - Withdrawal notice to Local Authority (added)
    - NHS Continuing Healthcare (CHC) status (added)
- End of Life care
- Estimated prognosis (added)
- Awareness of prognosis (added)

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- DNA-CPR (added)
- Additional support plans section (added)
- Over the counter medications (added)
- Primary support reason (added)

Webinar 3: About Me

Webinar 3 was held on 19th May 2020. There was a total of 85 attendees representing a wide range of health and social care disciplines as well as people who use services and their carers. 28% of the attendees were care home staff, social workers or healthcare professionals, 20% were service users or carers and 5% were from local authorities. It should be noted that a number of attendees from the pathfinders were also local authority staff or representing care providers). A list of the attendees is included in Appendix I.

The webinar covered the first draft of the standard, in particular whether any of the categories of information should be combined or kept separate considering what would make it easiest for the service user to complete and for a professional to find the information they need. The following categories were included in the first draft of the standard: (Note that reasonable adjustments are included but as a separate section, not within About Me. It was discussed at the webinar because of its link to About Me.)

About Me		
What and who is important to me	My nutrition	My emotions, mood and behaviour
Me at my best or on a normal day	My sleep	My work and learning
My likes and dislikes	My medications and treatment	Symptoms or conditions that affect my daily living
How I communicate	My mobility and movement	Date
My routines	My memory and thoughts	Supported to write this by

Reasonable Adjustments	
Reasonable adjustments	Impairments

Key themes and outputs from Webinar 3 are set out below:

Themes	Description	Quotes / Comments
Consolidation of sections	Consolidate a n umber of the sections because of overlap but	"information needs to be succinct; people need guidance on what the categories mean, otherwise there is a risk it will

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	separate What and Who is important to me into two categories	include too much irrelevant information that won't be read. Video is an ideal way to capture someone clearly and succinctly and should be available for all categories." - **Personalised Technology Manager**
		"I think it's important to keep what and who separate as for different people these things can carry different significance on a day to day basis" **– Service user**
		"What and who are very different" **– Service user**
		"For someone entering hospital in an emergency this me at my best is critical - especially for someone without communication.**"- Parent carer**
		"I think do and don't sections can be really helpful in providing key information quickly and accessibly" **– Service user**
		"From a medical doctor's perspective, medical records are notorious for capturing people when they are at their worst and so if you look back through the hospital records and GP records you find lots of stories about how people are when they're having a bad day, when they're delirious or unwell. It is very important to have the counter-narrative which is how good someone can be when they are at their best. This helps contextualize things for the medical staff, but it can also provide diagnostic information – how far someone has moved from what is normal for them." **– Geriatrician**
		"…to approve the care package [it] needs to say how that person is at their worst to justify the eligibility criteria as per the Care Act. My perspective is that the About Me needs to say something about what I am at my worst and my lowest hence why I need to support the most." **– Social worker**
Purpose and value of About Me	Its use for health and social care is for direct care and not for assessing the support needs of an individual It is not about what the professional wants to see, it is	"About Me is the single most important change in listening to people with needs. It is important in ways which I don't think are visible unless you know what to look for. It represents a sea change in the way we look at people with needs." **– Parent carer**

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	about what the individual wants to share	"Need to be clear that that assessment is based on need and money whilst the care and support plan is around a person's wishes and how they wish to use the support as outlined in care act." **– Social worker** "When [she] interacts with social care she always talks about how she is on her worst day because that is more likely to get her the support that she needs. When she interacts with healthcare it is different, as the Doctor would need to whole spectrum about health care and that is different" **- Carer/service user** "About me should not be for only those with especially complex needs. It should also be for people who have e.g. chronic conditions (metastatic cancer, Crohn's disease) and things about them and their condition management that really matter." **– Geriatrician** "the success of the standard will be in its ability to bring out patient voice with context (In my opinion). Both over and under providing information can be an issue, and one of the complaints with free text in any standard. From the conversation yesterday, what I took away was a clear message the about me is less about 'what the clinician is looking for', rather setting context and human perspective to the clinical information that is accessible in wider parts of the record." **– Business Analyst**
Multi-media use	Value of multi-media vs concerns about storage, access etc.	"multimedia needs to play a greater part, since that is the preferred format for many people." **– Systems supplier** "my only concern would be around 'maturity' of the systems. Ambulance trust systems for example, may or may not have capabilities that enable audio/video" **– Business Analyst**
Recording and use of About Me alongside other information	The About Me is one part of a shared care record and must sit alongside other important information such as End of Life Plans, Care Plans, Reasonable Adjustments, Medications, Allergies. There is a clinical risk that if	Preferences for care; Where I want to be cared for, where I would like to die, my preferences about the gender of a carer. These are preferences that have been indicated as being useful within 'About me' **– Business Analyst** "EoL preferences highlights the risk with

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important clinical information in an About Me is not also included in the relevant sections of the shared care record e.g. allergies, EoL preferences etc.

Consideration must be given to how the information will be recorded (including if the person does not have capacity to do so themselves) and updated.

How can we ensure that it will be used by professionals and other staff?

how this gets implemented. Monitoring of an about me is a risk. We know, rightly or wrongly, that processing of information is often more black-and-white for a clinical perspective. Somehow there needs to be balance. This is no easy task." **– GP**

"I think this has to be about governance and working with [people who use services] to ensure that they do not inadvertently add critical data without that be[ing] reflected in critical parts of the system" **- GP**

"As a Social Worker, with routines I'm documenting what care and support a given person needs, how often that is, when that is and what that person is going to be doing to support the person who needs the care. I think that information is most suited to a care plan rather than an About Me section." **– Social worker**

" I like the differentiation between 'About Me' and 'About You' - There's no doubt that much of the About You information will be vital to certain practitioners/professional doing their job effectively, however that information is already covered in existing standards (e.g. Core Information Standard). Restricting About Me to information the individual/patient is providing themselves (or via a proxy), gives the standard focus – it makes it more about how best to engage with a person on an individual level, enabling practitioners to give a personalised service rather than a standard offering based on clinical fact/findings" **– Business Analyst**

"I would argue very strongly [About Me] shouldn't be embedded in any document it should be its own thing as part of your single record which we draw on in our clinical documentation." **– GP**
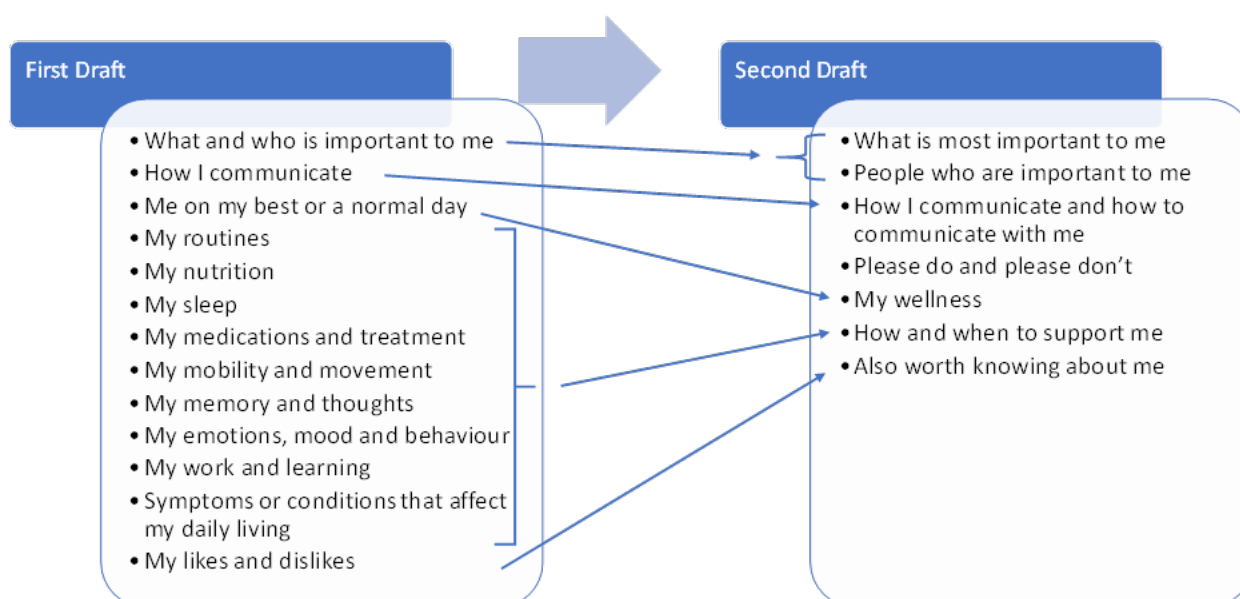
"How would we know that front-line health and care workers know how to utilize the patient information?" **– Researcher**

"Guidance on completing and using the info[rmation] is key" **– Parent carer**

"My experience, as someone who has

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		provided copious and, in my view, well-structured and clearly laid out documentation around my son's needs - it is not read." **– Parent carer**

The resultant changes to the About Me section are set out in the diagram below:

First Draft
- What and who is important to me
- How I communicate
- Me on my best or a normal day
- My routines
- My nutrition
- My sleep
- My medications and treatment
- My mobility and movement
- My memory and thoughts
- My emotions, mood and behaviour
- My work and learning
- Symptoms or conditions that affect my daily living
- My likes and dislikes

Second Draft
- What is most important to me
- People who are important to me
- How I communicate and how to communicate with me
- Please do and please don't
- My wellness
- How and when to support me
- Also worth knowing about me

Webinar 4: Urgent Referral from Care Home to Hospital

Webinar 4 was held on 21 May 2020. There was a total of 68 attendees representing a wide range of health and social care disciplines as well as people who use services and their carers. 38% of the attendees were care home staff, social workers or healthcare professionals, 6% were service users or carers and 7% were from local authorities. It should be noted that a number of attendees from the pathfinders were also local authority staff or representing care providers). A list of the attendees is included in Appendix J.

The aim of the webinar was to identify the essential information needed when a care home resident is transferred to hospital in an emergency. The discussion was based on the first draft of the standard which was developed follow the mapping of PRSB standards to the information currently included in the Red Bag based on the 'hospital pack' developed as part of the Sutton pathfinders programme. Where an information component already existed in the PRSB this was re-used. A small number of new requirements were identified including a nursing summary of the care needs of the individual and a record of over-the-counter medications.

The following information components were included in the first draft of the standard:

Demographic and administrative/ legal information	Referral Information	Baseline Information	Additional Medical Information (current and history)	Needs, wishes and preferences

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Person demographics	Referral details (who)	Examination findings and observations	Allergies and adverse reactions	Reasonable Adjustments
GP details	Return response to	Assessments	Medication Administration Record	Care needs summary
Professional contacts	Presenting complaints or issues	Investigation results		Additional support plans[17]
Personal contacts	History of each presenting complaint or issue			About Me
Deprivation of Liberty Safeguarding	Management to date			Cardio-pulmonary resuscitation
Safeguarding concerns				Advance statement
Risks				Anticipatory Actions
				Anticipatory Medicines / Equipment
				Preferred place of care
				Preferred place of death

Key themes and outputs from Webinar 4 are set out below:

Themes	Description	Quotes / Comments
Essential information or useful information	There is a balance to be struck between burden on care homes to provide large amounts of information in an emergency vs the information needs of the hospital. There is some information that must be sent by the care home at the point of referral (e.g. presenting complaints and issues) but there is other information	"Further information can be provided as necessary. If we call 999 we don't always have a lot of time to get the information together. We are fortunate in having electronic plans so can send [past medical history] and current needs along with MAR charts" **– care home manager**

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[17] This would include relevant support plans only e.g. a behaviour support plan or a moving and handling plan

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	that should be available should clinicians need it (medical history).	"Not overcomplicating is important, in central Bedfordshire they have packs ready to go in case of an emergency. These are updated once a month so it is only the most recent information that will need to be added before someone is taken to hospital" **– care home nurse** "The care as escalation record is completed at the time. In paper-based homes the "who I am", the CPR, the advanced care plan and the baseline assessment are all created before a person is going to hospital. This information is often put in a plastic wallet and called the red bag file and that gets photocopied alongside the latest MAR sheet and then they physically complete the carers escalation record as best they can in the time they have got." **– care home digital consultant** "For us in Leeds the "past medical history" is not that relevant we have a shared care record. It is important to have information explaining the medical symptoms that have triggered the referral, as if there is no carer, which is the current state of play with COVID, we will need to phone up the home" **– Consultant in Emergency Medicine** "[a] related challenge is how information is presented which may be a question for tech details: right balance of "push" & "pull" in the sense that information is layered. Critical information being pushed and details/ related issues easily accessible when needed without going through multiple steps/clicks in an information system" **– Doctor** "We need to remain mindful of information overload: therefore, need agreement/clarity on what is essential information needed to support safe care & clinical decisions" **– Doctor** "The information here needs to be part of the care homes day-to-day

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		care planning processes; or it may be a burden to keep up-to-date and continuity of care for the individual" **– systems supplier**

"The challenge … as a geriatrician receiving people into your care is that you are beholden to other people's summaries. There is an evidence-based approach to managing older people in acute settings … called [a] comprehensive geriatric assessment which states you need a relatively broad understanding of someone's situation. It's important to have a summary document go to a piece of information and it's important also to have sufficiently comprehensive information underpinning that for the people receiving the patient who are joining together some of the dots". **- Geriatrician** |
| **Best source of information** | Information such as current (active) and historic problems/diagnoses and procedures are important but information may need to come from sources other than the care home as the care homes may not hold all the information | "Many care homes are now equipped to collect a NEWS2 score independent of the shared care record with baselines, history and current score at the time the call was made to HCPs leading to the hospital admission, this can be collected as part of the assessment and observation information" **– System supplier**

"not sure if presenting information is just the escalation issues, or the usual [e.g.] dementia status, cognition, continence, mobility i.e. the non-presenting issue that hospital still needs to know about." **– Doctor**

"It would be essential for me as a doctor receiving somebody in hospital to know their past and active conditions. The question is whether we think this is better populated from care home data or somewhere else. I can't look after someone properly if I don't know their past medical history and active conditions as well as their presented complaint." **– Geriatrician** |

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		"it is vital information. Whether this is readily available and whether they have the definitive medical information in a care home, or a second-hand version is important." - **GP** "my experience has been that the "medical issues" part of the care home record is often the least up to date. For example, when we do a region wide audit of care homes in the East Midlands, the part home staff often feel unable to complete is "medical conditions"" **– Geriatrician** "Care homes [with] digital care plan systems have a summary sheet that includes the [past medical history] that they have to update on a monthly basis from [a] discussion with [the] GP" **– Nurse at a care home** "I think a care home (based on our 1600 homes) have more detail about the impact on the person about the medical conditions...maybe diagnosis is different" **– systems supplier** "If a care home doesn't have the medical history then how are they able to provide the appropriate care either. Surely this issue needs to be sorted out." **– Systems supplier**
Additional information		"I think it is important to include copies of any Power of Attorney documents so the hospital knows who can make decisions and what kind in the event of losing mental capacity" **– Social worker** "One could argue the MCA would need to be redone within the hospital as it is time and decision specific." **– Consultant in Emergency Medicine** "MCA & related decisions are needed even if the attending team will need to decide what they redo and what they need not repeat" **– Doctor**

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		"would be good to know [MCA] baseline, [I] agree [it] would be done on admission but [it would be] good to know what is normal" **– Doctor** "Another thing which is quite useful to know, and which may not automatically come is whether or not this person has had other admissions, attendances or significant incidents, for example have the paramedics been called, is something happening with increasing frequency." **- Geriatrician**	

The resultant changes to the Urgent Referral from Care Home to Hospital standard are set out in the table below highlighted in blue:

Demographic and administrative/ legal information	Referral information	Baseline information	Additional medical and social information (current and history)	Needs, wishes and preferences
Person demographics	Referral details (who)	Examination findings and observations	Allergies and adverse reactions	Individual requirements (including Reasonable Adjustments, mobility)
GP details	Return response to	Assessments	Medication Administration Record	Care needs summary
Professional contacts	Presenting complaints or issues	Investigation results	**Problem list**	Additional support plans[18]
Personal contacts	History of each presenting complaint or issue		**Procedures**	About Me
Deprivation of Liberty Safeguarding	Management to date		**Medications (including over-the-counter medications)**	Cardio-pulmonary resuscitation
Safeguarding concerns			**Social context**	Advance statement

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[18] This would include relevant support plans only e.g. a behaviour support plan or a moving and handling plan

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Risks				Anticipatory Actions
Mental Capacity Assessment				Anticipatory Medicines / Equipment
Mental Health Act or equivalent status				Preferred place of care
Consent for information sharing				Preferred place of death
Consent for treatment				**Contingency plans[19]**
Advance decision to refuse treatment				
Lasting power of attorney				
Property and equipment				
Documents				

Valuesets

Three online webinars were held with NHS Digital's nominated terminologist to assign terminology to new elements (unless they were free text) and check terminology for existing valuesets.

Online surveys

Two separate online surveys covering the five areas of focus to capture views on the draft information standards from a broader range of multi-disciplinary professionals and people who use services. The first survey ran from 22nd June 2020 to 24th July 2020 and covered three topics: Local Authority Information (for Shared Health and Care Records), Care Homes View (of Shared Health and Care Records) and About Me. The second survey ran from 30th June 2020 to 2nd August 2020 and covered two topics: Hospital Referral for Assessment for Community Care and Support and Urgent Referral from Care Home to Hospital.

Detailed findings from the surveys can be found in the survey reports (Appendices J and L of this report – separate documents).

Summary findings are below:

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[19] This would include plans which set out what should and should not be done if their health or wellbeing gets worse or if they have a crisis. These are often known as contingency, crisis or anticipatory plans.
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Survey 1: About Me

The survey asked different questions for health and care professionals and staff from patients and carers. There was a separate 'easy read' version of the survey which is reported on separately.

Responses from health and care professionals and staff

In the questions for health and care professionals and staff 68% of respondents thought additional information did not need to be captured in an About Me. Where other information was suggested, it was based on the following themes:

- **History of the person** (especially but not exclusively for people with dementia) "….the ability to talk to them about important people and events from their past life provides a better quality of care." (**A prompt for this information was added into the description for the 'Also worth knowing about me' category in the implementation guidance.**)
- **Preferences** – what someone likes to be called, End of Life (End of Life preferences should be held elsewhere in the health and care record, however if someone choses to record this information in their About Me it should be checked against the record and other areas of the record updated if appropriate).
- whether they have an **Advance Decision, Lasting Power of Attorney for Health and Welfare, DNACPR form and/or a ReSPECT form** in place. These should be recorded elsewhere in the heath and care record but if someone chooses to record this information in their About Me it should be checked against the record and other areas of the record updated if appropriate. (**A prompt for individuals completing an About Me to consider adding references to any other documents containing their preferences, such as an Advance Decision, was added to the implementation in the 'What is most important to me' category**.)

76% of respondents thought it would be 'easy' or 'very easy' to find the relevant information about the person in the About Me although this was caveated by comments such as it depends how it is set out and presented on the screen, the relevant facts could get lost if there is a lot of narrative provided and information would have to be easy to access, in a busy workplace with slow IT systems and already multiple passwords to remember its often easier and quicker to ask the person directly rather than search through more systems.

91% of respondents said it was important to differentiate in the About Me between important information – information that you 'must know' about an individual - and information that is 'worth knowing'. Others have said that:

- "all the information is important to me otherwise I wouldn't have included it"
- "there is a risk that staff only read the "Must Know" information"
- "that judgement [about what is most important] may change and may be different in different circumstances"

A note has been added to the implementation guidance to support this stating that most

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important information should be at the top of an About Me. In addition, there are separate categories for 'What is most important to me' and 'Also worth knowing about me'.

67% of respondents said it would be helpful if this information was presented in multi-media files e.g. short video clips and pictures however, 72% said that there would be potential barriers to using multi-media files with reasons such as time, IT and confidentiality cited.

80% had no concerns with this information being part of a health and care record but concerns were raised about how and who would be able to access the information and keeping the information current.

Responses from people using services and carers

83% of people who use services and 60% of carers thought there was a need to separate information into important information that the health or care professional 'must know' and information that is 'worth knowing'.

57% of people who use services and 50% of carers had no concerns with sharing this type of information. Concerns raised were maintaining confidentiality and maintaining control of the information if it were electronic.

60% of people who use services and 63% of carers thought it would be helpful to share the information as video clips / pictures. **Therefore, the standard allows for multi-media files or free text information.**

The results of the 'easy read' survey shows broad support for the About Me. Quantitative results were as set out below:

Question	Number of respondents	Yes	No	Not sure
Q1: Are the 7 things in the list the most important things that doctors and nurses should know about you in an emergency?	65	72%	14%	14%
Q2: Would having a list like this help you get the right support from your carers and support workers?	52	73%	19%	8%
Q3: Should there be 2 lists, the first for really important information and the second for other information?	51	55%	16%	29%
Q4: Are you worried about sharing your	50	16%	74%	10%

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information with the NHS and people who support you?				
Q5: Would it be ok to share your information using pictures and short videos?	48	50%	35%	15%

Survey 1: Local Authority Information (for Shared Health and Care Records)

The majority of respondents said that the information from the local authority set out in the draft standard was 'very important' or 'important' for health and care professionals to have access to. A concern was raised about sharing safeguarding information due to the sensitivity of the data that may be contained, however having access to the information would provide a more complete picture of the person. A number of suggestions were made about including details about equipment by care home staff however, this information is not generally recorded by Local Authorities and therefore was not included in the standard.

Survey 1: Care Homes View (of Shared Health and Care Records)

The majority of care home staff responded that most of the information set out in the proposed Care Homes View (of Shared Health and Care Records) was either 'important' or 'very important' (Range: 81% to 98%). The exception was for the section 'organ and tissue donation" (65%). They also thought that determining who should have access to the information should be for care home 'managers' (nominated individuals responsible for services as defined by the CQC) to decide.

In order to test the role-based access proposal for the Care Homes View (of Shared Health and Care Records); health and social care professionals were asked about whether only registered practitioners or all care home staff should be able to access certain information such as risks, medications, allergies, investigation requests, investigation results, examination findings, assessments, documents and end of life care (Range: 57% to 96%). With the exception of investigation requests, investigation results and examination findings (Range: 60% to 63%), the majority of respondents favoured that all staff should have access to all the information.

Following discussion with the clinical advisors and taking into account the outcome from the updated CIS Clinical Safety Case (See Hazard 47: 'Inappropriate role-based access (RBAC) implementation'; Hazard 50: 'The care homes view of the CIS record does not include some important information') it was concluded that the RBAC proposal was not supported by the consultation (see Care Homes View (of Shared Health and Care Records) guidance, separate document).

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Survey 2: Hospital Referral to Local Authority[20]

86% of respondents agreed that from the perspective of the person receiving care the standard contains appropriate information to allow their care expectations to be met. 79% of respondents agreed that from a carer's point of view the standard contains appropriate information to allow their care expectations to be met.

Suggestions were made on information that respondents thought may be missing from the standard. Following analysis, it was found that the majority of the suggestions were already included however **one new element was added to cover NHS Continuing Healthcare assessments.**

A number of respondents emphasised the importance of not overwhelming the end-user with too much information.

Survey 2: Urgent Referral from Care Home to Hospital

61% of respondents said a photograph is 'very important' or 'important' as it provides clues to disease states and needs, and not just when they are well. This data can be taken as support for the adoption of regular photographic uploads as a standard for all medical records, as well as imaging of particular problems, e.g. leg ulcers, pressure sores. **It was therefore included in the standard under 'Person demographics'.**

84% of respondents said access to information on recent GP consultations, ED attendances and admissions is 'very important' or 'important' because it is critical to understanding if there is a pattern of health and care that might indicate other problems that need to be addressed, for example safeguarding concerns or unaddressed needs, should the person have frequent falls etc. Some respondents commented that it should be available in integrated records and the information should come directly from the source e.g. GP records and it should be a recent history as large amounts of historical information would have limited value. **'Contacts with professionals' (covering GP consultations and ED attendances) and 'Admission details' covering admissions were therefore added into the standard.**

48% of respondents said information about participation in research (i.e. that the care home resident is currently participating in research) is 'very important' or 'important' if the resident was part of a clinical trial and particularly if it involved medication. **Following discussion with the clinical advisors it was agreed to add 'Participation in research' to the information standard.**

74% of respondents said pregnancy status is 'very important' or 'important' particularly if the resident is of child-bearing age, **therefore 'Current pregnancy' was added to the standard.**

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[20] *NB*: The survey was conducted before the standard was renamed Hospital Referral for Assessment for Community Care and Support

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Respondents overwhelmingly supported inclusion of social context information (support for educational history was lower than for other social context information) in the standard. **Therefore, 'Social context' was included in the standard.** This is necessary to truly enable holistic and person/relationship centred care by improved understanding of who the person is or was. The hospital may need to make decisions on behalf of a person who lacks capacity and can only do so in their best interests if they have an idea of how they would have responded or lived their lives previously.

A common theme recurring in the comments was that much of the information defined in the standard should be available as part of an integrated care record.

Other comments included that all the information will facilitate hospital professionals to meet their job requirements. All care homes differ but some hold lots of electronic information about the resident that would be invaluable to clinicians when the resident is in hospital. The issue is how to not make it a burden for care home staff and how to structure the information effectively and make it easy to access and action for professionals.

Vendor webinar and clinical informatician consultation

The vendor webinar was specifically targeted at systems suppliers (however a number of the suppliers that were involved also took part in earlier webinars) to gain their views on the latest version of the standards and their feedback on implementation. The information models and implementation guidance (where drafted for the five areas of focus) were posted on MS Teams providing the opportunity for clinical informaticians and vendors to review the documentation and provide feedback.

The webinar attendees are set out in Appendix K

Key themes identified and discussed by the stakeholders, which were predominantly related to implementation of the About Me standard, are paraphrased below:

- How will non-statutory providers e.g. charities etc. be influenced to use and adhere to the standards?
- Use of About Me: How can we make sure that information recorded in an About Me (by an individual or someone acting on their behalf) does not contradict information elsewhere in the health and care record and is added to other parts of the record if necessary? For example, if an individual documents a need that should result in a reasonable adjustment (which had not previously been identified by professionals); it will only be reflected in other parts of the record if a professional reads the About Me, identifies the need and requirements for a reasonable adjustment and records it in the individual's record. There is a need for processes to be put in place to ensure that an individual's About Me is read and used by professionals.
- How does the About Me relate to the reasonable adjustments and care plans? It is expected that there will be some level of duplication between information recorded by

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the individual in their About Me and care plans and reasonable adjustments recorded by professionals. They are not the same however as the About Me allows the individual to record what is important to them from their perspective and reasonable adjustments and care plans record needs and how those needs will be addressed by the service and those caring for or supporting the individual.

- If About Me information is easily updated by the individual or their carer, it may be more likely to be up to date than records held by the local authority or GP so it is important that the latest information is made available to all professionals (with a legal basis for accessing the information) in contact with the individual.

- The importance of education institutions as purveyors of information about people, especially around transitions to adulthood.

- The processes around when an individual or their parent / carer is asked to record (and update) an About Me needs to be defined.

- The example prompt questions for About Me are generally the same as those asked during a social care assessment. As these aren't designed to be used to feed a person's views into such an assessment, there is a danger that adults may feel they're answering the same questions multiple times. This was the driving force behind the single assessment / common assessment. The prompt questions are simply examples of what types of questions individual's may want to consider when recording an About Me. An individual can record whatever they wish in an About Me. It is not meant to be prescriptive – they should record whatever they want to share with health and care professionals.

- The use of multi-media is proven as advantageous for accessibility and inclusion in the About Me information sphere, however many rural areas have very poor internet connectivity, both in terms of wireless and fixed line connections so there may be barriers to accessibility. That's not a reason to not do it, but those in not-spots should not be disadvantaged as a result. There is also the issue of storage. Connectivity is critical to a digital model of integrated care and therefore needs to be resolved.

- How do legal documents e.g. power of attorney for health and welfare get transferred when these documents are in written format?

- Consent needs to be reviewed in line with the current thinking on "legal basis for proceeding". This is particularly pertinent when a significant proportion of population have no capacity, so cannot consent.

Digital Social Care Information Clinical Safety Case Summary

Background:

The NHS Digital Clinical Safety Group (CSG) operates a full Clinical Safety Management System (CSMS) that encompasses integration with health organisations and professional bodies. The essential structures of a CSMS have been implemented in this project through the consultation with healthcare professionals, patients, informaticians and clinical system suppliers, during the development of the Digital Social Care Information products. As part of the Clinical Safety Case for the Digital Social Care Information Project, PRSB has produced the following four deliverables:

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- Transfers of Care Clinical Safety Case Report
- Transfers of Care Hazard Log
- Core Information Standard Clinical Safety Case Report (addendum / new version)
- About Me, Care Homes View (of Shared Health and Care Records), Local Authority Information (for Shared Health and Care Records) Hazard Log (for incorporating into the Core Information Standard Hazard Log)

PRSB will send these deliverables to the NHS Digital CSG for approval. These will then be published on the PRSB website. Updates to the clinical safety case is the responsibility of PRSB.

Methodology:

The CSO monitored the execution of the Clinical Safety Case and ensured that clinical safety obligations were discharged.

Hazard Identification and Clinical Risk Analysis:

- Safety issues identified by clinical informaticians, clinical and professional advisors and patient advisors participating in hazard workshops on 8th July and 15th July 2020
- Safety issues identified by clinical informaticians, clinical and professional advisors and patient advisors participating in clinical safety meeting on 19th August 2020
- Potential clinical safety issues identified by stakeholder participants during consultation surveys (n=763) and other consultations undertaken during the development of the Digital Social Care Information products
- Production and review of a hazard logs (including mitigation and calculation of residual risk) and drafting of project reports
- NHS Digital clinical safety case review (pending)

Summary findings and recommendations

Transfers of Care: All hazards were identified through the consultation processes carried out to assure the two Digital Social Care Information products relating to transfers of care, which includes the following:

- Urgent Referral from Care Home to Hospital
- Hospital Referral for Assessment for Community Care and Support

Core Information Standard: All hazards were identified through the consultation processes carried out to assure the following Digital Social Care Information products:

- About Me
- Care Homes View (of Shared Health and Care Records)
- Local Authority Information (for Shared Health and Care Records)

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The consultation process for the clinical safety case is described in the Transfers of Care Clinical Safety Care Report and Core Information Standard Clinical Safety Care Report (update in progress).

During the consultations, hazards were identified, reviewed and mitigations / actions considered. Nevertheless, some risks are inherent in the standards, but most have been:

- mitigated during the development of the standards (including the clinical safety case)

or

- the residual risk has been transferred (with guidance) to the implementers

Hazards with a residual risk of 3 are outside the control of PRSB and cannot be mitigated by the PRSB. These risks are therefore handed on to the deployers of the standards. The majority of hazards (either in relation to transfers of care or the updated CIS) are rated as a risk acceptability level of 2. That is regarded as an acceptable level of risk. However, developers and implementers should take note of the risks and where possible try to minimise them. It is important that this guidance in relation to those hazards, regarded as system issues, become requirements for implementation.

4. Findings and Recommendations

Themes	Findings	Recommendations	Evidence / Comments
Implementation of About Me	Wide-spread support that a proportionate About Me will support delivery of person-centred care. Concerns that information recorded in an About Me is not consistent with, or reflected elsewhere in, the electronic record and the information is not acted upon by professionals	Piloting and evaluation of the new and revised standards through the pathfinders. Test the processes associated with individuals creating and updating an About Me. Develop and test guidance and processes for professionals using information in an About Me. Undertake wide-spread engagement programme with professionals to drive culture and process change in the use of information in the About Me.	"About Me is the single most important change in listening to people with needs. It is important in ways, which I don't think are visible unless you know what to look for. It represents a sea change in the way we look at people with needs." **– Parent carer** "As someone who has provided copious and, in my view, well-structured and clearly laid out documentation around my son's needs - it is not read." **– Parent carer** "I think this has to be about governance and working with [people who use services] to ensure that they do not inadvertently add critical data without that be[ing] reflected in critical parts of the system" **- GP**

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Use of multi-media in About Me	Use of multi-media for sharing About Me information would likely help people with communication difficulties and provide baseline information to professionals. However concerns were raised about confidentiality (accessing video or audio information in busy workplaces), storage of the files, ability to access multi-media through existing systems (e.g. ambulance systems), time to view (scanning written information is faster) and lack of connectivity.	Piloting and evaluation of the use of multi-media format for sharing About Me information within different population groups across different geographies. Test access to multi-media files for About Me in different settings and geographic areas e.g. A&E departments, Ambulance, care homes, mental health hospitals and GP practices.	"Many rural areas have very poor internet connectivity, both in terms of wireless and fixed line connections so there may be barriers to accessibility" 67% of health and social care professional and staff responding to the survey on About Me said it would be helpful if this information was presented in multi-media files e.g. short video clips and pictures however, 72% said that there would be potential barriers citing time, IT and confidentiality as potential barriers 60% of people who use services and 63% of carers thought it would be helpful to share About Me information as video clips / pictures. 50% of respondents to the easy read survey thought video clips and pictures would be helpful.
Shared health and care record vs transfer of care standards	Many of the information requirements identified in the transfers of care standards would ideally be fulfilled by a shared health and care record (with information from the source rather than the care home) with just the information relevant to the referral and recent baseline information about the resident / patient sent at the time of the referral. Shared records would address the issue of the recent change in policy guidance about discharge from acute hospital with support needs assessments now taking place in the community rather than the acute hospital.	Continue to drive the implementation of shared health and care records across ICSs and STPs.	"For us in Leeds the "past medical history" is not that relevant [as] we have a shared care record. It is important to have information explaining the medical symptoms that have triggered the referral, as if there is no carer, which is the current state of play with COVID, we will need to phone up the home" **– Consultant in Emergency Medicine** In response to the survey on the Hospital Referral for Assessment for Community Care and Support standard a number of comments related to a large information burden to be transferred and the importance of system design to ensure information is communicated clearly. Responses to the survey on referral from care home to

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			hospital: "This information will be useful but much of it will either not be held by the care home or if it is held may be out of date. It may not be possible to collate and or copy it in an emergency situation. It may also be too much information and in reality a succinct summary may be more useful." "Be careful that the differentiation between required information to be provided and information which is accessible through sharing are not mixed up…A single version of the truth will minimise confusion. Determine where shared data should reside to reduce the need to copy data in order to fill in a referral."
Digital maturity of care homes	Digital maturity in care homes is mixed – only about a quarter of care homes have electronic care planning and record keeping systems. This impacts their ability to share information with health care professionals electronically – unless care homes meet the required data security and protection standard they will not be able to access health and care information via shared health and care records.	Work with care providers to improve levels of digital maturity, supporting them to achieve the standards set out in the data security and protection toolkit (including information governance and training of staff) and the implementation of standards compliant digital systems. Commission technical FHIR (Fast Healthcare Interoperability Resources) message specifications to ensure a complete set of materials for implementation.	The CQC report Beyond Barriers, July 2018: "Effective information sharing across organisational boundaries means that staff working in different organisations are able to access people's records to make informed decisions about people's needs and care requirements. We saw some good practice in some systems. However, in the main, information sharing remained a significant challenge for systems" "In the absence of fully integrated record sharing and to improve communication and coordination, we saw examples of systems co-locating multidisciplinary staff from across health, social care and the VCSE sector. By having different information systems in the same room, this enabled quicker and easier information sharing."
Access to health and	Care home staff should be provided access to all (not	As above	Survey 1 found that the proposed Role-Based Access

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care information in care homes	partial) information in a shared health and care record on a needs basis with access controlled by the care home manager.		Control (different "views" of information in a shared health and care record for care home managers and registered professionals from other staff working in the care home) was rejected. It was strongly rejected by respondents for the following sections: Risks (92.00% against), Medications and medical devices (79.67% against), Allergies and adverse reactions (95.65% against), End of life care (86.34% against). The RBAC proposal was also rejected by a slight majority for Assessments (64.67% against) and Documents (57.38% against).
Separate standard to support Local Authority information sharing	In addition to enhancements to the Core Information Standard to include information from the Local Authority, it was identified that a separate standard to support the transfer of Local Authority information into a shared health and care record was also required to encourage contributions from Local Authorities.	That the Core Information Standard is enhanced to support Local Authority information (in the next scheduled release) and the standard for Local Authority Information (for Shared Health and Care Records) is published.	The decision to create both a separate standard for the information that should be shared by Local Authorities with health and social care professionals and enhancements to the Core Information Standards was taken at the June Project Board meeting (24/06/2020). This was discussed in webinar 1 and there was agreement that a separate standard was required: "a standard across all authorities would be very welcomed" **– IT lead (LA)** "Embedding the standard into local authority working practise is important, there is no real kind of standard coding behind a lot of this [information]." **– Business Analyst** "if are going to share information with Local Authorities then a standard would be welcome, if not essential" **– CTO, care provider**
Access to up-to-date,	Concerns were raised about how information such as	Conduct work on the sharing of legal and end of	Issue raised in the vendor consultation webinar about

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accurate end of life and legal information	power of attorney, Advance Decision to Refuse Treatment, Do Not Attempt CPR can be made available to health and care professionals (as the documents exist in written format) so that they can be confident of the provenance of the information and that it is accurate and up-to-date and not make decisions based on erroneous information.	life information such as power of attorney, advance decisions and Do Not Attempt CPR notices to develop proposals for how the information could be shared to ensure there is the ability to transmit the latest clinically and legally binding decisions in an electronic format (these documents are currently required to be written and signed). Elements relating to consent in the standard will require review when the new national guidance on the lawful basis for data sharing is released. Consent for treatment also requires review.	how legal documents e.g. power of attorney for health and welfare get transferred. Issue raised in the vendor webinar about the correct recording of consent for both data sharing and treatment, particularly if the person does not have capacity to consent.
Implementation of standards in non-statutory providers	Encouraging implementation in non-statutory providers (e.g. independent sector and charities) will require different levers and incentives.	Continue to work with software suppliers through networks and associations such as CASPA to ensure that the digital systems comply with the standards (potential to accredit systems). When care providers purchase new digital systems, they should ensure that systems are compliant with the standards.	Raised in vendor consultation webinar. 78% of social care jobs are in the independent sector. The NHS plan considers standards implementation in NHS organisations.

5. Discussion and conclusions

There was strong, broad support that proportionate About Me information will support the delivery of person-centred care by enabling individuals to share what is important to them with health and care professionals. This should be prominent in any electronic patient record. However, concerns were raised about information in About Me not being consistent with, or reflected elsewhere in, the electronic record and the information not being acted upon by professionals. These concerns should be addressed by undertaken wide engagement with professionals on the purpose and use of About Me to drive the necessary culture and process changes.

Individuals (or someone acting on their behalf) should be able to record and update the information in their About Me at different points in their life, including during childhood. The

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processes for how and when individuals can create and update an About Me should be defined and tested with different population groups.

It was found that the use of multi-media for sharing About Me information would undoubtedly help people with communication difficulties and provide baseline information to professionals. However, concerns were raised about confidentiality (accessing video or audio information in busy workplaces), storage of the files, ability to access multi-media through existing systems (e.g. ambulance systems), time to view (scanning written information is faster) and lack of connectivity in some areas (wireless and fixed line connections) limiting accessibility. These concerns should not prevent the use of multi-media file sharing in shared care records as people are interacting increasingly using video and audio communications but they should be tested as part of pilots in different geographic areas and different settings e.g. in care homes, in GP practices, in ambulances and in emergency departments.

Professionals identified a significant amount of essential information that would be required in the two transfer of care standards. It is expected that much of the information would eventually be provided by enabling access to a shared health and care record (shared record) rather than transferring it at the time a person is transferred. (This would apply, for example, to information such as history of problems or diagnoses or medications and allergies.) Access to shared records would enable such information to be provided from source e.g. the GP record or the hospital record and ensure a single source of the truth. Some information, however, would need to be transferred with the person at the point of transfer such as the reason for the referral and any recent assessments or observations (not held within the shared record) that would provide baseline information for receiving professionals. There is a national drive to implement local health and care records through the Local Health and Care Record programme and subsequent work funded and supported by NHSX to rollout shared records within Integrated Care Systems (ICS) and Sustainability and Transformation Partnerships (STPs) and this will help to remove some of the burden on care home staff in providing all the information at the point of referral and ensure clinicians have access to the latest information on the patient from the most appropriate source.

In addition, care homes differ widely in their digital maturity. A large number are still paper-based. The burden on care home staff may increase if they attempt to send all the information set out in the Urgent referral from care home to hospital standard (regardless of whether much of the paperwork is pre-prepared) when a resident is being referred in an emergency and it may delay the transfer. The existing 'Red Bag' process (on which this standard is based) currently requires a large amount of paper information (much of which is pre-printed) and key findings from a previous evaluation of the 'Red Bag' was that the physical documentation often gets lost during the transfer of the patient, it can be incomplete and it can be time consuming to generate. The evaluation therefore recommended better use of IT in the process. This standard is an enabler for achieving that objective, however its implementation must be concurrent with a drive to increase digital maturity across care homes. The Urgent Referral from Care Home to Hospital and the Hospital Referral for Assessment for Community Care and Support standards should be piloted in areas where there are existing shared health and care records and areas whether

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there are not and areas of high and low digital maturity in care homes to identify any changes required to minimise the burden in these different environments.

In addition, in order for care home staff to have access to health and social care information held in shared records the organisation needs to demonstrate a level of digital maturity and compliance with the expected standard for health and social care to hold, process or share personal data[21]. Care homes should continue to be supported to achieve the standard in the data security and protection toolkit (including information governance and training of staff). Work with software suppliers for care providers should continue to ensure that the digital systems comply with the standards (there is potential to provide accreditation) so that when care providers purchase new digital systems, they are compliant with the standards. Fast Healthcare Interoperability Resources (FHIR) technical messaging specifications should be commissioned to complete the package of resources required to implement these standards in practice.

The consultation on the information care home staff should have access to from a shared record concluded that in principle all staff caring for or supporting the person should be able to access the information (rather than some staff having access to a subset of the information depending on their role) because of the clinical risk of having access to partial information, and it should be the responsibility of the care home 'manager' (nominated individual responsible for services as defined by the CQC) to provide and restrict access via appropriate role-based access control (RBAC) mechanisms.

The consultation on Local Authority Information (for Shared Health and Care Records) confirmed that the information Local Authorities should contribute to a shared care record and that standard should be both an enhancement to the Core Information Standard and a standard in its own right to encourage the contributions from Local Authorities. The updated to the Core Information Standard will be published in the next scheduled release however the standard for Local Authority Information (for Shared Health and Care Records) will be published on conclusion of this work.

Health and care professionals need to know that vital information about end of life preferences exists, such as Advance Decisions to Refuse Treatment, Do Not Attempt CPR and Lasting Power of Attorney for Health and Welfare, and that it is up-to-date. This information can have an incredibly positive effect on the quality of a person's death. Equally, however, concerns have been raised about how this information can be made available to health and care professionals so that they can be confident of the provenance of the information and that it is accurate, up-to-date (in particular as currently it needs to be in writing and signed) and not make decisions based on erroneous information. Further work is required to consider how information that is generated on paper with clinically and legally binding decisions could be shared in an electronic format. In addition, the elements relating to both consent for information sharing and consent for treatment require future review when anticipated new national guidance regarding the lawful basis of data sharing is released.

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[21] The Department of Health and Social Care recommend that all social care providers complete the data security and protection toolkit (https://www.dsptoolkit.nhs.uk/)

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In August 2020, the Department of Health and Social Care issued revised policy on the hospital discharge process developed in response to COVID-19. Acute hospitals are required to discharge patients as soon as it is clinically safe to do so. Social care needs assessments and NHS Continuing Healthcare (NHS CHC) assessments of eligibility should mostly be made in a community setting and not take place during the acute hospital inpatient stay. This means that the context of the "Hospital Referral for Asssessment for Community Care and Support" has changed as the assessment for support now takes place after discharge. The information defined in the standard will still be required to assess the care and support needs of an individual after discharge, however it may be that it will not be transferred by the hospital to the Local Authority. This reinforces the need to move to shared records where much of the information needed could more easily be made accessible to professionals within multi-disciplinary teams from multiple organisations at the same time.

Although the NHS plan sets out that it will "mandate and rigorously enforce technology standards to ensure data is interoperable and accessible" this will also be required within social care. However, a recent study[22] found that local authorities prefer local standards to nationally mandated standards. In addition, as the majority of providers are independent sector and non-statutory providers (e.g. charities) different levers and incentives will be required to drive the implementation of standards for information sharing in this sector. It will be important to continue to work with networks and associations like the Care Software Providers Association (CASPA), who bring together systems suppliers for social care providers, to implement the standards in practice.

The current standards use the Medicines and Healthcare products Regulatory Agency (MHRA) definition (to which the NHS data dictionary is also aligned) of a medical device which includes items "for the purpose of… compensation for an injury or handicap" for example spectacles, hearing aids, wheelchairs and walking sticks. However, this requires future review and updating following preliminary feedback from clinicians on where they would expect to find a record of such items.

The joining up of health and social care is continuing at pace. Around half of England is now covered by ICSs which involves greater collaboration between NHS organisations, local councils and others to deliver better joined-up person-centred care and support. Joined-up working must be underpinned by shared information and these new information standards contribute to that goal. There is an opportunity now to work with the pathfinders and systems suppliers to test and refine the standards and then rollout more widely to support the national aims for ICSs and shared health and care records.

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[22] https://www.local.gov.uk/local-government-social-care-data-standards-and-interoperability

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6. Appendices

6.1. Appendix A – Project Board Members

Name	Organisation	Role
Prof Maureen Baker CBE	PRSB	Chair
James Palmer	NHS Digital	SRO
Lorraine Foley	PRSB	Senior Supplier
April Farrant	NHSX	Policy lead Social Care Standards and Interoperability
Eleanor Maw	NHSX	Policy Advisor
Luke Heselwood	NHSX	Policy Lead - Social Care Strategy and Innovation
Athena Arvaniti	NHS Digital	Senior Project Manager
June Nicholas	NHS Digital	Project Manager
Samantha Bergin-Goncalves	N/A	Citizen Lead
Professor Adam Gordon	University of Nottingham	Secondary Care Lead
Dr John Robinson	N/A	GP Lead and Clinical Safety Officer
Katie Thorn / Ian Turner	Registered Nursing Home Association	Care Home Lead
Beverley Latania	Chair of the Principal Social Worker network for adult social care	Social Care Lead

6.2. Appendix B - Professional and lay advisors

Name	Role
Samantha Bergin- Goncalves	Citizen Lead
Katie Thorn	Care Home Lead
Beverley Latania	Social Care Lead
Professsor Adam Gordon	Secondary Care Lead
Dr John Robinson	GP Lead and Clinical Safety Officer

6.3. Appendix C – Project team

Name	Role
Martin Orton	PRSB Director of development and delivery

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Sarah Jackson	Project Manager - PRSB
Sandip Kaur	PRSB Business Analyst
Annette Gilmore	PRSB Clinical Analyst and Nurse
James Critchlow	Associate Researcher (UCL & PRSB)

6.4. Appendix E – Questions used in mixed-media consultation

1. Tell me the key things that someone caring for you needs to know about you? For example, this might be how you communicate
2. What would help someone caring for you know you at your best? For example, this might be a photo, video, information about what you like to do
3. What would someone caring for you need to know about what makes you feel happy? For example, this might be interests/hobbies e.g. listening to music, spending time with family
4. What would someone caring for you need to know about what makes you feel physically and mentally good day by day? For example, this might be sleeping well, eating well, not being in pain
5. What would someone caring for you need to know about who is important to you and why? For example, this might be family, friends
6. What would someone caring for you need to know to help you feel safe and relaxed in difficult situations? For example, going to hospital or when your routine changes
7. What would someone caring for you need to know to recognise when you are unwell? For example, you may become very quiet, seek a comforting item
8. Is there anything else you think is important that hasn't been covered?

6.5. Appendix F – Participants in mixed-media consultation

Number	Role
14	Service user
3	Sibling of service user
3	Daughter of service user
7	Parent carer
Frances Johnston	Speech and Language Therapist
1	Parent of service user
3	Support worker
1	Granddaughter of service user
1	Wife of service user
Richard	Specialist Music Therapist
Vicky Sacre	Hospice Care Assistant

6.6. Appendix G – Webinar 1 attendees

Name	Organisation	Title / Role
Alannah McGovern	PRSB	Membership manager
Anca Costinas	NHS South West London CCG	Senior Transformation Manager – Commissioning and Planning (Wandsworth CCG)
Andrew Coles	Patient Centred Software (Sutton)	Product Manager
Annette Gilmore	PRSB	Clinical Analyst and Nurse
Athena Arvaniti	NHS Digital	Senior project manager, social care programme
Ben Williams	Hft	PT Co-ordinator
Bev Latania	Principal Social Worker network for adult social care	Chair (social worker)
Caroline Pollington	NHS South West London CCG	Senior Quality Manager
Chau Nguyen	DXC Vietnam	Business Analyst
Cheryl Stimson	Central Bedfordshire Council	Project Manager - Service Development - Social Care, Health & Housing
Clare Cottrell	NHS Digital	Project manager, social care programme
Clare Swan	Woodchurch House	Home Manager
Daniel Hollingworth	Nourish Care	Head of Customer Experience (previously General Manager at a Residential Care Home)
David Waller	NHS Digital	Benefits lead, interoperability

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Dr Ian McNicoll	freshEHR Clinical Informatics Ltd.	Former GP and Director
Dr John Robinson	Royal College of General Practitioners	Retired GP
Dr Malte Gerhold	Birdie	Chief Integrated Care Officer
Eileen Nutting	Dignity in Care	Chair - Merton's Senior Forum
Emma Nichols	Hft	Personalised Technology Manager
Emmeline Crawley	Papillion Homecare Ltd	Registered Manager
Fran Husson	Imperial College London	Public Partner
Grant Attwood	Right at Home North Somerset	Managing Director
Harriet Soderberg	South Central and West CSU	Project Manager
Hayley Miller	Leeds Care Record	Senior digital project manager
Hayley Mozley	Kirklees Council	IT Senior Officer
Hazel Parsons	Warwickshire County Council	Quality and Contract Monitoring Officer
Heidi Koikkalainen	freshEHR Clinical Informatics Ltd.	Editor
Helene Feger	PRSB	Director of comms, communication, and engagement
Iain Carpenter	PRSB	Retired Geriatrician
Ian Haywood	NHS Dorset CCG	Business Analyst
Jackie Harris	NHS Digital	Project lead - supporting Wolverhampton/ Worcestershire
James Critchlow	UCL Institute of Health Informatics	Associate Researcher and Project Team (PRSB)
James Palmer	NHS Digital	Programme Head- social care programme
Jamie Smith	Intercare services	Head of Operations
Jennifer Davis	Westwood residential	Registered Manager
Jeremy Baldwin	Nourish Care	Chief Product Officer
June Nicholas	NHS Digital	Project Manager
Karan Jarvis-Keysell	Design & Learning Centre Kent	Workforce project officer, learning disability & mental health
Katie Thorn	Registered Managers' Network	Digital Engagement Manager
Kay Nicholls	Hft	Registered Cluster Manager - Devon
Keith Aldridge	NHS Digital	Senior Project Manager - social care programme
Keith Strahan	NHS Digital	Principle Clinical Lead - Social Care Programme (social worker)
Kerry McCrossan	Worcestershire County Council	Operations and Integration Lead

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Laurella Morgan-Bruce	Oxleas Digital	Project manager, clinical transformation team
Leah Squire	Katherine Putko	Senior UX/ UI developer
Lindsey Farrow	Leeds City Council	Project Support Officer - City Digital Partnerships Team
Lizzie Cernik	PRSB	Comms officer
Lorenzo Gordon	Maldaba (Hft)	Co-Founder
Lorraine Foley	PRSB	CEO
Lucy Mcculloch	London Borough of Sutton	Care Home Digital Integration Consultant
Lucy McKell	NHS Digital	Project leader - supporting National Care Forum
Maisy Griffiths	HealthWatch	Area Lead - South Gloucestershire
Martin Orton	PRSB	Director of development and delivery
Nasiv Toor	NHS Digital	
Natasha Neads	NHS South, Central and West Commissioning Support Unit	Project Manager MBCS, RITTech
Nicky Kirkland	Worcestershire County Council	Project Manager
Nicola Rodwell	Oxleas Digital	Project Support and Training Officer - Clinical Transformation Team
Prapichaya Prommas	Keio University	PhD in Medicine
Prof Adam Gordon	British Geriatric Society	Clinical Associate Professor in Medicine of Older People
Rebekah Doherty	Person Centred Software	
Richard Gladman	Yorkshire and Humber Care Record	Trust Non-Exec Director and Programme Manager
Samantha Goncalves	PRSB	Citizen advisor
Sandip Kaur	PRSB	Business Analyst
Sarah Duxbury	Hft	Registered Cluster Manager
Sarah Jackson	PRSB	Programme Manager
N/A	N/A	Service user
Sarah Sheppard	Commissioning Support Unit, Warwickshire County Council	Senior Occupational Therapist
Sarah-Jayne Woodman	CornwallCare	Senior Nurse
Sean Higginbotham	Nottinghamshire County Council	Assistive Technology Workstream Lead
Sharon Wedgbury	Contract Management and Quality Assurance Commissioning Support Unit Warwickshire County Council	Delivery lead

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Stephen Handley	Nottinghamshire County Council	Senior BA
Taffy Gatawa	everyLIFE technologies limited	Chief Information and Compliance Officer
Tim Chalklen	Abicare Services Ltd	Chief Technology Officer
Tom Harrison	Wellcome Trust	Senior Policy Officer
Tommy Henderson-Reay	National Care Forum	Digital Transformation lead and registered social worker
N/A	N/A	Family carer
Zoe Halliday	NHS Arden and Greater East Midlands CSU	Training specialist
Zoe Whatmore	Manchester Clinical Commissioning Group	Senior Information Analyst

6.7. Appendix H – Webinar 2 attendees

Name	Organisation	Title / Role
Alannah McGovern	PRSB	Membership manager
Andrew Coles	Patient Centred Software (Sutton)	Product Manager
Annette Gilmore	PRSB	Clinical Analyst and Nurse
Athena Arvaniti	NHS Digital	Senior project manager, social care programme
Ben Wilson	Orion Health	Product Solution Group Lead
Bev Latania	Principal Social Worker network for adult social care	Chair (social worker)
N/A	British Heart Foundation	Service user and carer
Chau Nguyen	DXC Vietnam	Business Analyst
Cheryl Stimson	Central Bedfordshire Council	Project Manager - Service Development - Social Care, Health & Housing
Clare Cottrell	NHS Digital	Project manager, social care programme
Daniel Hollingworth	Nourish Care	Head of Customer Experience (previously General Manager at a Residential Care Home)
David Waller	NHS Digital	Benefits lead, interoperability
Don Shenker	Health Innovation Network	Senior Project Manager
Dr Hashim Reza	Royal College of Psychiatrists	Clinical Director of Informatics
Dr Ian McNicoll	freshEHR Clinical Informatics Ltd.	Former GP and Director
Dr John Robinson	Royal College of General Practitioners	Retired GP
Dr Malte Gerhold	Birdie	Chief Integrated Care Officer
Emma Nichols	Hft	Personalised Technology Manager
Fran Husson	Imperial College London	Public Partner
Graham Walker	Cerner	Integration Architect, National Standards Practice

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Hayley Mozley	Kirklees Council	IT Senior Officer
Heidi Koikkalainen	freshEHR Clinical Informatics Ltd.	Editor
Helene Feger	PRSB	Director of comms, communication and engagement
Iain Carpenter	PRSB	Retired Geriatrician
Ian Haywood	NHS Dorset CCG	Business Analyst
James Critchlow	UCL Institute of Health Informatics	Associate Researcher and Project Team (PRSB)
Jamie Middleton	Sheffield Health & Social Care NHS Foundation Trust	Lead Professional (forensic social worker)– Social Work & Social Care
Jamie Smith	Intercare services	Head of Operations
June Nicholas	NHS Digital	Project Manager
Karan Jarvis-Keysell	Design & Learning Centre Kent	Workforce project officer, learning disability & mental health
Katie Thorn	Registered Managers' Network	Digital Engagement Manager
Kay Nicholls	Hft	Registered Cluster Manager - Devon
Keith Aldridge	NHS Digital	Senior Project Manager - social care programme
Keith Strahan	NHS Digital	Principle Clinical Lead - Social Care Programme (social worker)
Kevin Woodcock	East Riding of Yorkshire Council	ICT Strategic Solutions and Systems Manager
Laurella Morgan-Bruce	Oxleas Digital	Project manager, clinical transformation team
Lindsey Farrow	Leeds City Council	Project Support Officer - City Digital Partnerships Team
Lizzie Cernik	PRSB	Comms officer
Lorenzo Gordon	Maldaba (Hft)	Co-Founder
Lorraine Foley	PRSB	CEO
Lucinda Kalupka	Home Counties Carers Ltd	Registered Manager
Lucy McKell	NHS Digital	Project leader - supporting National Care Forum
Maisy Griffiths	HealthWatch	Area Lead - South Gloucestershire
Mark Bradford	Bristol City Council	Programme lead, Digital Integrated Health and Social Care
Martin Orton	PRSB	Director of development and delivery
Mary Busk	NHS England/ Improvement	Senior Family Carer Advisor, Learning Disabilities and Autism
Michelle Larke	Leicester City Council	Interim Lead Commissioner Social Care and Education
Nasiv Toor	NHS Digital	
Natasha Neads	NHS South, Central and West CSU	Project Manager MBCS, RITTech
Nicky Kirkland	Worcestershire County Council	Project Manager
Nicola Rodwell	Oxleas Digital	Project Support and Training Officer - Clinical Transformation Team
Nicola Rouse	Worcestershire County Council	Urgent Care Lead
N/A		Service user
Pam Garraway	NHS Digital	SRO for the Social Care Digital Programme

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Prapichaya Prommas	Keio University	PhD in Medicine
Prof Adam Gordon	British Geriatric Society	Clinical Associate Professor in Medicine of Older People
Rebekah Doherty	Person Centred Software	
Rosie Gilbert	Nottinghamshire County Council	Interim Transformation Manager (Mid Notts)
Samantha Goncalves	PRSB	Citizen advisor
Sandip Kaur	PRSB	Business Analyst
Sandra Baughan	Quic (Quality in Care)	Managing Director and Nurse Prescriber
Sarah Jackson	PRSB	Programme Manager
Sarah Sheppard	Commissioning Support Unit, Warwickshire County Council	Senior Occupational Therapist
Sarah-Jayne Woodman	CornwallCare	Senior Nurse
Sean Higginbotham	Nottinghamshire County Council	Assistive Technology Workstream Lead
Stephen Handley	Nottinghamshire County Council	Senior BA
Taffy Gatawa	everyLIFE technologies limited	Chief Information and Compliance Officer
Tommy Henderson-Reay	National Care Forum	Digital Transformation lead and registered social worker
Zoe Halliday	NHS Arden and Greater East Midlands CSU	Training specialist

6.8. Appendix I – Webinar 3 attendees

Name	Organisation	Title / Role
N/A	N/A	Service user
Alannah McGovern	PRSB	Membership manager
Andrew Coles	Patient Centred Software (Sutton)	Product Manager
Andrew McBride	everyLIFE Technologies Limited	Chief Product Officer
Athena Arvaniti	NHS Digital	Senior project manager, social care programme
Ben Wilson	Orion Health	Product Solution Group Lead
Bev Latania	Principal Social Worker network for adult social care	Chair (social worker)
N/A	British Heart Foundation	Service user and carer
Caroline Pollington	NHS South West London CCG	Senior Quality Manager
Chau Nguyen	DXC Vietnam	Business Analyst
Cheryl Stimson	Central Bedfordshire Council	Project Manager - Service Development - Social Care, Health & Housing
N/A	Also works for a care provider	Parent carer

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Clare Cottrell	NHS Digital	Project manager, social care programme
Crispin Hebron	NHS Gloucestershire Primary Care Trust	Learning Disability Consultant Nurse
Dalia Stasiulyte	City Digital Partnerships Team	Helm Project Manager
Daniel Casson	Care England	Digital Development Executive
Daniel Hollingworth	Nourish Care	Head of Customer Experience (previously General Manager at a Residential Care Home)
David Waller	NHS Digital	Benefits lead, interoperability
Don Shenker	Health Innovation Network	Senior Project Manager
Dr Ian McNicoll	freshEHR Clinical Informatics Ltd.	Former GP and Director
Dr Katherine Middleton	Birdie	Clinical Product Lead and Generalist Medic
Emma Nichols	Hft	Personalised Technology Manager
Emma Vardy	Salford Royal NHS foundation trust	Consultant Geriatrician and Clinical dementia and delirium lea
Fran Husson	Imperial College London	Public Partner
N/A	N/A	Family carer
Harriet Soderberg	South Central and West CSU	Project Manager
Heidi Koikkalainen	freshEHR Clinical Informatics Ltd.	Editor
Helene Feger	PRSB	Director of comms, communication and engagement
Iain Carpenter	PRSB	Retired Geriatrician
Ian Haywood	NHS Dorset CCG	Business Analyst
Jackie Harris	NHS Digital	Project lead - supporting Wolverhampton/ Worcestershire
James Critchlow	UCL Institute of Health Informatics	Associate Researcher and Project Team (PRSB)
Jamie Middleton	Sheffield Health & Social Care NHS Foundation Trust	Lead Professional (forensic social worker)– Social Work & Social Care
Jeremy Baldwin	Nourish Care	Chief Product Officer
John Cooling	Solcom Ltd	Chair
Jonathan Papworth	CASPA	Co founder - person centred software
Juli Atkinson	Bexley Voice Parent Carer Forum	Parent participation coordinator
June Nicholas	NHS Digital	Project Manager
Karan Jarvis-Keysell	Design & Learning Centre Kent	Workforce project officer, learning disability & mental health
Katie Clarke	Bringing us together	Executive Director and Co-Founder
Katie Thorn	Registered Managers' Network	Digital Engagement Manager
Katy Else	Livewell Southwest	Social Worker
Kay Nicholls	Hft	Registered Cluster Manager - Devon
Keith Aldridge	NHS Digital	Senior Project Manager - social care programme
Keith Strahan	NHS Digital	Principle Clinical Lead - Social Care Programme (social worker)

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Laurella Morgan-Bruce	Oxleas Digital	Project manager, clinical transformation team
Lesley Andrew	Signature Senior Lifestyle	General Manager Wandsworth Common
Lisa Hunt	Hft	Personalised Technology Co-ordinator
Lizzie Cernik	PRSB	Comms officer
Lorenzo Gordon	Maldaba (Hft)	Co-Founder
Lorraine Foley	PRSB	CEO
Lucy Mcculloch	London Borough of Sutton	Care Home Digital Integration Consultant
Maisey Dear	North East Essex Clinical Commissioning Group	Care Homes Nurse
Marion Burgess	Parent Carer Forum	Chair
Martin Orton	PRSB	Director of development and delivery
Mary Busk	NHS England/ Improvement	Senior Family Carer Advisor, Learning Disabilities and Autism
Nasiv Toor	NHS Digital	
Natasha Neads	NHS South, Central and West Commissioning Support Unit	Project Manager MBCS, RITTech
Nicky Kirkland	Worcestershire County Council	Project Manager
Nicola Rodwell	Oxleas Digital	Project Support and Training Officer - Clinical Transformation Team
N/A		Service user
Paula Anderson RN MFCI	University College London Hospital	CNIO
Pauline McLean	Orion Health	Clinical Consultant (nurse)
Prapichaya Prommas	Keio University	PhD in Medicine
Prof Adam Gordon	British Geriatric Society	Clinical Associate Professor in Medicine of Older People
Rebekah Doherty	Person Centred Software	
N/A	N/A	Service user
Samantha Goncalves	PRSB	Citizen advisor
Sandip Kaur	PRSB	Business Analyst
Sarah Hadley	Oxleas NHS Foundation Trust	Head of Music Therapy
Sarah Jackson	PRSB	Programme Manager
N/A	N/A	Service user
Sarah-Jayne Woodman	CornwallCare	Senior Nurse
Shri Mehrotra	HealthWatch Sutton	Director
Stephen Handley	Nottinghamshire County Council	Senior BA
Steve Robinson	NHS Digital	Senior Project Manager - Integration projects

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Sue Gale	Local Government Association	Assistant Director, Transforming Care
Taffy Gatawa	everyLIFE technologies limited	Chief Information and Compliance Officer
N/A	N/A	Service user
Tom Harrison	Wellcome Trust	Senior Policy Officer
Tommy Henderson-Reay	National Care Forum	Digital Transformation lead and registered social worker
N/A	N/A	Family carer
N/A	N/A	Family carer

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Appendix J – Webinar 4 attendees

Name	Organisation	Title / Role
Alannah McGovern	PRSB	Membership manager
Andrea Robinson	Hft	Quality and Improvement Manager
Andrew Coles	Patient Centred Software (Sutton)	Product Manager
Andrew McBride	everyLIFE Technologies Limited	Chief Product Officer
Annette Gilmore	PRSB	Clinical Analyst and Nurse
Athena Arvaniti	NHS Digital	Senior project manager, social care programme
Ben Wilson	Orion Health	Product Solution Group Lead
Bev Latania	Principal Social Worker network for adult social care	Chair (social worker)
Caroline Pollington	NHS South West London CCG	Senior Quality Manager
Chau Nguyen	DXC Vietnam	Business Analyst
Cheryl Stimson	Central Bedfordshire Council	Project Manager - Service Development - Social Care, Health & Housing
Clare Cottrell	NHS Digital	Project manager, social care programme
Daniel C W Henning FRCEM FFCI	Royal Navy and RCEM informatics committee	Surgeon Commander & Consultant Emergency Physician
Daniel Hollingworth	Nourish Care	Head of Customer Experience (previously General Manager at a Residential Care Home)
Dr Andy Webster	RCEM/ Leeds Teaching Hospital	Consultant in Emergency Medicine/CCIO
Dr Hashim Reza	Royal College of Psychiatrists	Clinical Director of Informatics
Dr Ian McNicoll	freshEHR Clinical Informatics Ltd.	Former GP and Director
Dr John Robinson	Royal College of General Practitioners	Retired GP
Dr Katherine Middleton	Birdie	Clinical Product Lead and Generalist Medic
Emma Nichols	Hft	Personalised Technology Manager
Fran Husson	Imperial College London	Public Partner
Graham Walker	Cerner	Integration Architect, National Standards Practice
Harriet Soderberg	South Central and West CSU	Project Manager
Heidi Koikkalainen	freshEHR Clinical Informatics Ltd.	Editor
Helene Feger	PRSB	Director of comms, communication and engagement
Iain Carpenter	PRSB	Retired Geriatrician
Ian Haywood	NHS Dorset CCG	Business Analyst
James Critchlow	UCL Institute of Health Informatics	Associate Researcher and Project Team (PRSB)
Jamie Middleton	Sheffield Health & Social Care NHS Foundation Trust	Lead Professional (forensic social worker)– Social Work & Social Care

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Jo Flippance RN	Bedfordshire Care Group Ltd	Care Network Project Support Officer / Trusted Assessor
John Cooling	Solcom Ltd	Chair
Jonathan Papworth	CASPA	Co-founder - person centred software
Karan Jarvis-Keysell	Design & Learning Centre Kent	Workforce project officer, learning disability & mental health
Katie Thorn	Registered Managers' Network	Digital Engagement Manager
Keith Aldridge	NHS Digital	Senior Project Manager - social care programme
Keith Strahan	NHS Digital	Principle Clinical Lead - Social Care Programme (social worker)
Laurella Morgan-Bruce	Oxleas Digital	Project manager, clinical transformation team
Leah Squire	Katherine Putko	Senior UX/ UI developer
Lesley Andrew	Signature Senior Lifestyle	General Manager Wandsworth Common
Lindsey Farrow	Leeds City Council	Project Support Officer - City Digital Partnerships Team
Lisa Hunt	Hft	Personalised Technology Co-ordinator
Lizzie Cernik	PRSB	Comms officer
Lorenzo Gordon	Maldaba (Hft)	Co-Founder
Lucy Mcculloch	London Borough of Sutton	Care Home Digital Integration Consultant
Maisey Dear	North East Essex Clinical Commissioning Group	Care Homes Nurse
Martin Orton	PRSB	Director of development and delivery
Michael Bell	Croydon Health Services NHS Trust	Chairman
Nasiv Toor	NHS Digital	
Natasha Neads	NHS South, Central and West Commissioning Support Unit	Project Manager MBCS, RITTech
Nicky Kirkland	Worcestershire County Council	Project Manager
N/A		Service user
Olivia Sperring-Jones Contractor	NHSX	Content lead
Pauline McLean	Orion Health	Clinical Consultant (nurse)
Prof Adam Gordon	British Geriatric Society	Clinical Associate Professor in Medicine of Older People
Raphael Nosce	Hft	Supported Living Worker
Rebekah Doherty	Person Centred Software	
Rosie Harper	NHS	Band 6 Rotational MSK Physiotherapist
Sandip Kaur	PRSB	Business Analyst
Sandra Baughan	Quic (Quality in Care)	Managing Director and Nurse Prescriber
Sarah Jackson	PRSB	Programme Manager
N/A		Service user
Sarah Sheppard	Commissioning Support Unit, Warwickshire County Council	Senior Occupational Therapist

Sarah-Jayne Woodman	CornwallCare	Senior Nurse
Shri Mehrotra	HealthWatch Sutton	Director
Taffy Gatawa	everyLIFE technologies limited	Chief Information and Compliance Officer
Tommy Henderson-Reay	National Care Forum	Digital Transformation lead and registered social worker
Zoe Halliday	NHS Arden and Greater East Midlands CSU	Training specialist

6.1. Appendix K – Webinar 5 attendees

Name	Organisation	Title / Role
Alex Wren	Clinical Architecture	Healthcare informaticist
Andrew Coles	Patient Centred Software (Sutton)	Product Manager
Andy Minnion	Rix Research and Media (Hft)	Director
Annette Gilmore	PRSB	Clinical Analyst and Nurse
Behl Raman	NHS Digital	Physiotherapist and clinical leader
Ben Fitzgerald	Healthcare Gateway	Product Manager
Chris Sweeney	Liquidlogic	Adult social care lead
Clare Cottrell	NHS Digital	Project manager, social care programme
Dalia Stasiulyte	City Digital Partnerships Team	Helm Project Manager
Daniel Hollingworth	Nourish Care	Head of Customer Experience (previously General Manager at a Residential Care Home)
Diane Benton	Expertise Homecare	Operations Manager
Dr Andrea Dantas	Cerner	Director	Physician Executive
Dr Ian McNicoll	freshEHR Clinical Informatics Ltd.	Former GP and Director
Dr John Robinson	Royal College of General Practitioners	Retired GP
Dr Julian Costello	Royal College of General Practitioners	GP and informatician
Dr Michael White	University of Oxford	General Surgeon
Elizabeth Gaudin	Care rooms	COO
Emma Forsyth	Capita	Product Manager
Emma Melhuish GphC	NHS Digital	Principal Informatics Specialist
Fran Draper	South Central and West CSU	Engagement Lead & Senior Project Manager for the Connecting Care Partnership
Gary Brims	Philips	Solutions Consultant
George Noble	Kent community health NHS Foundation Trust	Community consultant
Heidi Koikkalainen	freshEHR Clinical Informatics Ltd.	Editor
Hui Teoh	NHS Digital	Principle technology specialist

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James Critchlow	UCL Institute of Health Informatics	Associate Researcher and Project Team (PRSB)
June Nicholas	NHS Digital	Project Manager
Kathy Farndon	Carbonel consulting Ltd	Healthcare management consultant and director
Katie Thorn	Registered Managers' Network	Digital Engagement Manager
Keith Strahan	NHS Digital	Principle Clinical Lead - Social Care Programme (social worker)
Laurella Morgan-Bruce	Oxleas Digital	Project manager, clinical transformation team
Madeleine Judge	Dorset County Hospital NHS foundation trust	Project Support - Health Informatics
Mark Chapman	Really Care	CEO
Mark Frayne	NHS Wales Informatics Service	Lead Applications Design Architect
Martin Orton	PRSB	Director of development and delivery
Michael Bond	NHS Digital	Clinical Informatics Manager
Natasha Neads	NHS South, Central and West Commissioning Support Unit	Project Manager MBCS, RITTech
Nicola Rodwell	Oxleas Digital	Project Support and Training Officer - Clinical Transformation Team
Oliver Wylie	Care rooms	NHS commercial lead
Pauline McLean	Orion Health	Clinical Consultant (nurse)
Prof Adam Gordon	British Geriatric Society	Clinical Associate Professor in Medicine of Older People
Rebekah Doherty	Person Centred Software	
Richard Kavanagh	Graphnet	Product Manager
Rob Hardisty	Graphnet	Patient hold record, manager
Robin Blay	techUK	Rep
Samantha Goncalves	PRSB	Citizen advisor
Sandip Kaur	PRSB	Business Analyst
Sarah Jackson	PRSB	Programme Manager
Sharon Jones	DXC	Partner engagement lead
Stephen Handley	Nottinghamshire County Council	Senior BA
Susan Maddock	Capita	Product Manager
Taffy Gatawa	everyLIFE technologies limited	Chief Information and Compliance Officer
Tom Russell	techUK	Programme Manager
Tommy Henderson-Reay	National Care Forum	Digital Transformation lead and registered social worker
Vincent Scaife	Hft	Personalised Technology Coordinator
Yasmine Kedoo	Cerner	Solution Architect

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