



**Professional
Record
Standards
Body**

**Better records
for better care**

Community Healthcare Services Discovery

FINAL REPORT

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Document Management

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Glossary of Terms

Term / Abbreviation	What it stands for
AHP	Allied Health Professional
CGA	Comprehensive Geriatric Assessment
CIS	Core information standard
CIC	Community Interest Company
CIO	Chief information officer
CCIO	Chief clinical information officer
CNIO	Chief nursing information officer
CSDS	Community Services Data Set
DICOM	Digital Imaging and Communications in Medicine
DTAC	Digital Technology Assessment Criteria
EPR	Electronic patient record
FHIR	Fast Healthcare Interoperability Resources
HL7	Health Level Seven
ICB	Integrated care board
ICD10	International classification of diseases
ICS	Integrated care system
ISN	Information Standards Notice
LOINC	Logical Observation Identifiers Names and Codes
NICE	National Institute for Health and Care Excellence
PCSP	Personalised care and support plan
PEOLC	Palliative and End of Life Care
PODAC	Podiatry, Optometry, Dentistry, Ambulance and Community
SHcR	Shared Care Record
SNOMED CT	Systematised Nomenclature of Medicine - Clinical Terms
TEP	Treatment Escalation Plan

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Executive Summary

In August 2023, the Professional Record Standards Body (PRSB) initiated a review into information standards within community health care services. The primary aims of this discovery project was to understand how health and care professionals, and people in receipt of care, could access the right information at the right time to make well-informed decisions. The focus was on identifying the necessary information standards for supporting direct care within community healthcare services by addressing 4 key questions:

- What information standards used by community health services are universal (across healthcare UK wide) standards?
- What information standards used by community health services are bespoke to the sector?
- What are the gaps, and would these standards be universal or bespoke?
- What is the stakeholder view of prioritisation of new standards?

Employing its established methodology¹, PRSB undertook research to see what information standards were pertinent to community health care services and supplemented this with consultation events including surveys, interviewed subject matter experts and people who use community services and stakeholder webinars to gather and validate findings.

The desk-based research identified several general health care standards and specialised standards that cover the delivery of community health care services. Additionally, there are technical standards that are relevant to community health care services, however there is no universal information standard in use.

The interviews, survey and webinars revealed that access to up-to-date, patient-centred information within frontline services is severely limited, directly impacting the quality of patient care. Furthermore, community health services organisations require an implementation support programme that tackles challenges related to people, processes, and technology.

There are technical and data standards^{4.1.14.1.3} used by community healthcare services, but they are not specific to the sector. The community services dataset is bespoke to community health services. It defines the data for a secondary uses collection and not for sharing information for direct care.

The clear gap is the definition of a community health services care record however, there is also an implementation gap for the existing standards and sharing of information between services, professionals and people which limits the effectiveness and quality of care. Data intended for planning and research purposes (secondary usage) should directly originate from point-of-care information wherever possible.

The PRSB's Core Information Standard has been identified as encompassing the essential data domains for supporting community health care delivery and, as the standard for shared care records, is becoming more widely used as shared care records are developed and implemented.

The stakeholder view of prioritisation is focussed on providing access to information from across the health and care system, so that care professionals have visibility of the care record from other organisations.

¹ [About Us – PRSB \(theprsb.org\)](https://theprsb.org)

There is support for more condition specific standards like diabetes, e.g. for other long-term conditions.

The recommendations include supporting shared care record implementation, exploring the adoption of the Core Information Standard for community care records, and potentially developing a phased roadmap for implementation.

The roadmap would entail adopting the Core Information Standard, incorporating care assessments, and supporting specialised clinical standards. It also suggests extending UK Core FHIR standards, providing implementation guidance for system suppliers, encouraging interim use of GP Connect, and offering holistic support packages for care providers.

A standardised patient engagement portal approach and alignment of community services datasets with selected standards are proposed, along with a follow-up on survey responses related to local data sharing and standards development. The executive summary emphasises the importance of these recommendations in fostering a cohesive and efficient healthcare information-sharing ecosystem.

1 Introduction

1.1 Background

There are over 800 community health care providers with a mix of NHS community trusts, Community Interest Companies (CICs), voluntary and private providers (of which approximately 150 deliver over 90% of community health services delivery). The sector has experienced historic under-investment in digital, data and technology which limits its capability to deliver against integrated care ambitions. The diversity of the sector, in number and type of provider and volume and variety of services delivered, provides a further challenge.

The Digital team (part of the of the Community Transformation Programme) has been created to support a portfolio of digital transformation projects across the NHS in England to ensure that there is a directed focus to ensure that community health services are able to harness digital technology building on the adoption of digital throughout the COVID-19 pandemic.

The purpose of this programme is to ensure community health services, as part of local systems, are supported to provide a comprehensive digitally enabled service that aspires to deliver evidenced-based care with a focus on maintaining high quality services, which are safe and effective use of resources. This will be enabled by:

- Valuing patient and staff experience with a focus on user-centred design.
- Recognising the challenges of health inequalities and digital inclusion; and
- Developing the capacity and capability across teams to deliver change.

To provide the step change in how the NHS cares for citizens, a common understanding on the digital standards for community health services providers is necessary to enable the delivery of integrated care through a common language across health and care teams.

There is a need for a discovery piece of work to understand what community services pathway information standards for direct care already exist and identify gaps where further work is needed to address those gaps identified.

There is also a known concern with the quality of existing data in community health services which needs to be taken into consideration as part of this work.

2 Aim and objectives.

The Professional Records Standard Body (PRSB) have been commissioned by NHS England to conduct a discovery project aimed at comprehending the existing information standards for direct care within community services pathways and identifying areas requiring further attention to address any identified gaps.

The aim for this discovery work is to understand what community services pathway information standards for direct care already exist and identify gaps where further work is needed, and prioritise those gaps identified.

This will contribute towards a list of standards which community health system suppliers will be required to conform with to be included in a new supplier catalogue. Conformance with these standards will support the sharing of information between systems and professionals and in turn support better integrated care for people.

The objectives for the discovery work and report were to answer the following 4 questions:

- What information standards used by community health services are universal (across healthcare UK wide) standards?

- What information standards used by community health services are bespoke to the sector?
- What are the gaps, and would these standards be universal or bespoke?
- What is the stakeholder view of prioritisation of new standards?

The work also considered how care professionals and people in receipt of care, and their carers could have the right information at the right time to make informed decisions.

The output provides recommendations leading towards a costed plan for the next phase of work.

The information standards are primarily to support direct and integrated care, but also to support population health, research, and service improvement.

3 Scope

3.1 In scope

Community health services are diverse in nature with the community services dataset identifying 58 types of community service that a person can be referred into², but to understand future priority areas, the discovery phase concentrated on the following service lines.

District Nursing Service	Speech and Language therapy services	Continence services	Crisis response intermediate care service
Rehabilitation service	Physiotherapy service	Podiatry services	Tissue Viability Service
Respiratory services	Occupational Therapy service	Nutrition and dietetics service	Cardiac service
Diabetes service	Long term conditions management service	Musculoskeletal service	End of Life service
Home based intermediate care	Neurology services	Reablement intermediate care service	Phlebotomy service
Community bed based intermediate care services	Virtual Wards		

The discovery work focused on services in England, however, did not exclude services in the other UK nations.

3.2 Exclusions from scope

The following areas were excluded from scope by NHSE to focus on the services listed above. The reasons for exclusion were either because work was underway or had recently been completed in these areas.

- Community care services not listed as in scope above.
- Maternity services
- Children (specific variations)
- Mental health services, including mental health therapies.
- Community pharmacy, optometry and dentistry are all out of scope.
- Urgent care

² Appendix 2 – Community Services Data Set (CSDS) v1.6 User Guidance - Health and Social Care Information Centre 2023

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- Hospices, except where they provide community services.
 - Primary care services
 - Social care services (social care stakeholders were in scope of the consultation)
 - Specific work for any of the devolved UK nations

4 Project approach

The project followed the PRSB's proven and trusted methodology³ as appropriate for discovery work.

The project team included professional, and person leads. The professional lead was not able to represent the full and very wide range of community services within the scope of the work but was able to bring the front-line view and insight of some services and provide valuable guidance to the work.

The project started with desk research, and a survey which were used to inform the later phases of the project, the subject matter expert interviews ran through out the project and evolved as the project progressed. Findings from the early survey and desk research were validated in the webinars.

4.1 Desk research

The project involved conducting desk research to identify existing standards, assessing whether they are universal or specific to community services. Additionally, it aimed to locate and analyse relevant NICE guidelines and other relevant professional recommendations. Furthermore, previous and expected PRSB work, such as shared care records and **PODAC** (which verified the use of the core information standard for all of Podiatry, Optometry, Dentistry, Ambulance and Community services), and relevant standards such as personalised care and support plan, diabetes, wound care, social prescribing, and nursing (in development) were reviewed.

4.1.1 Standards

The project researched what standards existed national and internationally, these included **Interoperability** standards such as FHIR (Fast Healthcare Interoperability Resources) and HL7 (Health Level Seven), **Terminology** standards such as SNOMED CT (Systematised Nomenclature of Medicine - Clinical Terms), **Vocabulary** standards – ICD10 (International classification of diseases), LOINC (Logical Observation Identifiers Names and Codes). There are also other relevant technical standards such as DICOM (Digital Imaging and Communications in Medicine).

The research also identified several countries that advocated a national direction on promoting the use of health information standards, e.g. Sweden, Denmark, Australia.

4.1.2 NICE Quality Standards

The National Institute for Health and Care Excellence (NICE) has published quality standards covering 7 of the 22 services in scope.

- End of life,
- rehabilitation,
- home-based intermediate care,
- reablement intermediate care service,
- diabetes,
- nutrition and dietetics and long-term conditions management services.

³ [About Us – PRSB \(theprsb.org\)](https://www.theprsb.org)

NICE published an early value guidance on virtual wards platform technologies acute respiratory infection in October 2023⁴.

4.1.3 Existing Information Standards Notices

The project identified the following information standards notices, that are relevant to the scope.

End of Life	SCCI1580: Palliative Care Co-ordination: Core Content This information standard specifies the core content to be held in electronic palliative care co-ordination systems (EPaCCS) and supports NHS England's objective to increase the use of technology to help people manage their health and care. End of Life API standards to enable sharing and updating of digital end of life care (EoLC) records
Diabetes	DAPB4085: Diabetes Record Information Standard (PRSB) An information standard to define the information needed to support a person's diabetes management, including self-management, across care settings.
Wound Care	PRSB standard defining the information record content for the management of wound care. The standard has 3 specific domains: Wound assessment treatment, Treatment plan and supporting self-care (self-management).
Community Services Data Set (CSDS)	Data for research and planning (secondary usages) Also referred to as DAPB1069, is a standardised dataset employed by community health services in the UK. It is a patient level, output based, secondary uses data about publicly funded Community Services. Secondary use of health data involves processing health information for purposes other than the ones it was originally collected for.
Personalised Care and Support Plan (PCSP)	Allowing the sharing of care plans between patients, carers and all the health and care professionals involved in a person's care

4.1.4 Other PRSB standards

The project identified that the following PRSB standards, are relevant to the services in scope.

Core Information Standard (CIS)	Defining a set of information that can potentially be shared between systems in different sites and settings, among professionals and people using services
Nursing Care Needs Standard	A new standard for use across all the different health and social care settings, this includes the care assessments and interventions that are a core part of nursing care across all health and social care settings
About me	The most important details that a person wants to share with professionals in health and social care

⁴ <https://www.nice.org.uk/guidance/hte13>

Palliative care and end of life (PEOL)	Update to the SCCI 1580 EoL standard for palliative and end of life care coordination to ensure that professionals and individuals have access to appropriate information to support decision making for those with palliative care needs and those who are approaching the end of their lives.
Diabetes	An information standard to define the information needed to support a person's diabetes management, including self-management, across care settings.
Wound Care	PRSB standard defining the information record content for the management of wound care. The standard has 3 specific domains: Wound assessment treatment, Treatment plan and supporting self-care (self-management).

4.2 Survey

An online survey was conducted via SurveyMonkey. The questionnaire intended to gather qualitative and quantitative data to inform the discovery project. The PRSB Communications, Engagement and Strategy team distributed the link via all streams. Simple plain-text language, which described the nature of the project, its aims and scope, was used when sharing the survey. The survey was shared through social media channels, emails and existing lists of stakeholders connected to the project. Users and carers of community care services were also engaged in the survey.

The survey, which was developed in in August 2023 and made available to stakeholders through PRSB and NHS England networks, consisted of specific questions to elicit information from service providers, clinical IT system suppliers and users about information standards in use across the UK, evaluation of the PRSB's Core Information Standard (CIS), gaps, and priorities of providers and users.

During the survey analysis, common themes emerged from the response, which related to the challenges regarding information record standards and digital integration in community care settings.

A total of 289 responses were received; 108 of these were totally excluded from the analysis as they contained only the health care professionals' role, not answering any of the detailed questions in the survey. A detailed analysis of the final 181 responses is contained in Appendix 1, but the key messages from the survey are as follows.

- 54% not aware of information standards
- 97% agreed that standards would be extremely useful or very useful.
- 86% agreed that SNOMED CT would be extremely useful or very useful.
- Information sharing - There's a need to incorporate linked professional contacts across a care pathway for better coordination.
- Several respondents commented about information sharing. Some comments reported about that the feedback loop from virtual fracture clinics and trauma meetings to urgent treatment centres is currently absent, leading to a lack of information sharing. In addition, patients referred by practice nurses for dressings at these centres often do not receive formal letters, indicating a gap in communication.
- One respondent suggested that a single, integrated record system with appropriate access for all stakeholders, including patients, would eliminate information-sharing delays and reduce patients repeatedly providing the same information, leading to a more patient-centred healthcare experience.

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- There's a need to incorporate linked professional contacts for better coordination. Additionally, integrating information from the third sector and social care is crucial for comprehensive care delivery.
 - Local hospice charities, which contribute significantly to patient care, are not adequately captured within the current systems.
 - The absence of a national system and the lack of interoperability among existing systems highlight significant challenges in information sharing across healthcare services.
 - There was some support for the development of specialised information standards such as has been developed for wound care, diabetes, and end of life care.

4.3 Stakeholder Meetings

4.3.1 Interviews

The project conducted interviews with CIOs, CCIOs, and CNIOs from major community trusts, as well as hosting interviews with key professionals, particularly allied health professionals (AHPs) identified in the stakeholder list.

Additionally, the project included meetings with clinical and professional leads from the NHS England community team and other key stakeholders, such as system suppliers.

19 interviews with subject matter experts. The focus of these interviews was to understand the information priorities at the point of care. A total of 27 people attended these interviews comprising.

- 14 staff from frontline organisations, these were a combination of clinical, care professionals and digital leads.
- 8 Policy
- 5 Suppliers

A full summary of the interviews is included in Appendix 2. The headlines from the interviews identified the following key messages.

The interviews highlighted the necessity for improved interoperability, access to patient history, and streamlined information flow across healthcare services to enhance patient care and support healthcare professionals in various disciplines. The key points raised in these interviews can be summarised as follows.

1. Information Access and Interoperability
 - Community-wide shared records are essential for accessing appointments, past medical history, and information from various services.
 - Access to patient history and consistent terminology in specialist treatment areas is necessary.
2. Healthcare Professional Access and Workload:
 - EPRs (Electronic Patient Record Systems) do not fully accommodate physiotherapists or single-handed professionals.
 - Implementation support, especially for agreed clinical terms, is required.
 - Scheduling in the community should consider travel time.
3. Standards and Support in Healthcare:
 - Core Information Standard (CIS) is extensive but might need clarification regarding outcomes and user experience.
 - AHPs (Allied Health Professionals) lack representation and support in current clinical systems.
4. Patient-Centric Approach and Portals:
 - Patient portals should include self-care technologies and patient-specific information, meeting GDPR standards.

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- About Me should reflect patient wishes and link to patient passports.
5. Data Sharing and Community Care Challenges:
 - Challenges exist in data sharing among independent providers and varying approaches in reporting.
 - Digital health information and system functionality need improvement in supporting care plans and communication.
 6. Virtual Wards and Monitoring:
 - Virtual wards rely on varied care pathways and tasks, leading to individual clinical variability.
 - Monitoring devices provide extensive data, posing challenges in determining relevance to care processes.
 7. EPMA and Medication Records:
 - EPMA (Electronic Prescribing and Medicines Administration) and a single medication record are crucial for streamlined information.
 8. Specialist Disciplines and Terminology:
 - Inclusion of 25 specialist AHP disciplines' terminology and support for outcomes measures is crucial.
 - Clinical systems lack support for AHPs, leading to varied record-keeping practices.
 9. Information Flow and Integration:
 - Integration of vital signs, clinical responsibility transfer, and access to education material for specialist disciplines are needed.
 - Access to social care information and the ability to share information across patient pathways is crucial.
 10. Implementation Challenges and Patient Information:
 - Support for community IT services and standard definition for services like Comprehensive Geriatric Assessment (CGA) is required.
 - Patient access to information and shared care records significantly reduces time to find patient information.

4.3.2 Service user testimonies

To understand the impact on people in receipt of community services, and their carers the project team commissioned a series of interviews with service users and their carer. These provide an important statement about the impact that not having information can have on the provision of care. For example, not having a hoist available for a wheelchair user's outpatients' appointment can mean that it is not feasible to proceed with the appointment which is disruptive to the person requires the rebooking of the appointment.

The main findings across the interviews with users and carers of community healthcare services include:

- Service users felt that the community health services did have the appropriate information; this was circumvented by the user informing the service providers independently, rather than being readily available and accessible online. This also led to many users and carers stating that repetition of information was common. One user expressed that their services did not have the right information at all, due to the rarity of their conditions, and the user provided leaflets to inform health services the right information so they could receive the right care.
- Overall, most users felt that the community health services could be improved; both users and carers advocated for the integration and implementation of Multi me⁵ across

⁵ Multi Me is a self-advocacy and person-centred planning platform for individuals with disabilities and their circle of people that support them in their daily lives.
<https://www.multime.com/>

all services, as it would empower and reinstate individuals to have control of their own care whilst allowing professionals to have comprehensive understanding of individuals' needs, communication styles, preferences, and aspirations.

An anonymised summary of the service user testimonies is included in Appendix 3

4.3.3 Webinars

Three webinars were used to validate and verify the findings and gaps from the earlier stages of the project. The webinars were open to all stakeholders, including front-line community care professionals for the in-scope services, as well as CIOs, CCIOs, and CNIOs from community providers and community care EPR system suppliers and included breakout groups that addressed three key points:

- Will shared care records (supported by the Core Information Standard) cover all the information that is necessary to provide high quality community health services?
- Could patient portals or other functionality, benefit from a standards definition?
- What implementation support would you require, for example would it be helpful to define community health services specific value sets against things like assessments and procedures?

There was clear support for the need for a comprehensive, standardised, and accessible patient centred information shared across the care pathway (and across organisational boundaries). Systems need to prioritise patient needs, interoperability, and usability for healthcare professionals. However, here was concern that, whilst the core information standard covers all the information that is necessary to support community health services, it is large and there is the potential to over burden care professionals.

The comments and observations can be summarised into the following key messages.

1. Information Sharing and Capture:
 - Capture comprehensive details for people in receipt of community care services, including special needs and communication requirements.
 - Improve information sharing between hospitals and community care to ensure continuity of care.
2. Patient Care Plans and Portals:
 - Develop patient-centric care plans accessible through portals with multimedia and patient-specific details.
 - Ensure patient consent, language accessibility, and inclusion of images.
3. Standards and Interoperability:
 - Standardise information across healthcare systems to ensure seamless integration and sharing.
 - Address challenges such as data ownership and interoperability issues.
4. Implementation Challenges and Support:
 - Provide support for implementing standards, training, data security, and ownership clarification.
 - Simplify information recording, prioritising a narrative approach over tick-box methods.
5. Patient-Centric Approaches:
 - Use patient-centred language and prioritise role-specific, relevant information for healthcare professionals.
 - Emphasise prioritisation of information based on different roles and responsibilities.
6. Patient Portals and Access to Information:
 - Ensure patient portals offer relevant information, reduce repetition, and maintain data security.

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- Enable access to pertinent information for healthcare professionals while ensuring ease of use.
7. Care Record Consistency and Management:
- Ensure consistency in care records, manage complex plans, define ownership, and maintain updated and accurate information.
 - Avoid overwhelming healthcare professionals with excessive standards while ensuring compliance.
8. Technological Integration and Tools:
- Utilise national tools such as the NHS App for interoperability and provide user-friendly interfaces across different devices.
 - Focus on the practicalities of implementing systems and tools to facilitate smoother workflows.

5 Analysis

The desk-based research identified several PRSB standards that cover the delivery of community health care services these include general health care standards.

- Core Information Standard,
- About Me
- Personalised Care and Support Plan,
- Nursing Care Needs Standard

There are also several specialised standards which also relevant to community health care services.

- Diabetes
- Palliative and End of Life Care Information Standard
- Wound Care Standard

Additionally, there are technical standards (see 4.1.1 above) that are relevant to community health care services,

Consolidating the evidence from the survey, the webinars and the interviews with service users and subject matter experts leads to the following observations. The statements below draw on the outputs from the survey, webinars and interviews and include comments that are indicative of the overall response. Full write-up of the survey, webinars and interviews are included in the appendices to this document.

Access to up-to-date, patient-centred information within frontline services is severely limited, directly impacting the quality of patient care. This is clearly seen from the statements in the service user testimonies and from comments from clinical staff at both the webinars and interviews.

"Some health services aren't good because they keep sending me to the poly clinic, which doesn't have any hoists. As a wheelchair user who can't get up or walk, it's a problem. They don't have the right information at all. They get everything wrong, especially at the medical centre. Whether they have hoists or not, considering I can't walk, seems like common sense."

"Care needs assessment - adult needs assessment is not consistent, typically providers have their own person focussed needs assessment, often intellectual property, PCSP would seem to meet the need, but could be supported by specific guidance".

"These information access challenges have significant implications for patient care quality. Essential clinical data, including test results, scans, and reports, often remain out of reach. Speech and language therapy (SLT)

notes from acute settings and shared care plans are also inaccessible, limiting the ability to deliver well-informed and patient-centred care. Inadequate access to hospital notes and assessments further compounds the problem, which underscores the urgent need for improved information sharing and system interoperability to enhance the overall healthcare experience and outcomes for patients.”

“Communication needs from the patient reflect reasonable adjustments and must be available to care professionals involved in the care of the patient”.

“There is no access to live system when out and about, although offline access is available which provides access to the clinical record of known patients (patients on the current caseload) emergency referrals, or unplanned patients are not available.”

There was strong and general support for the PRSB's Core Information Standard, which encompasses essential data domains for supporting community health care delivery being implemented across community health care services. There was also support for the personalised care and support plan.

“CIS seems to be appropriate, next of kin, progress notes and specialist plans (EoLC) needs to be available”.

“Multi-disciplinary teams require access to the Core information Standard information, and to the shared care record”.

The survey asked whether changes to CIS were needed. No changes were identified, those that were suggested related to areas that are already within the CIS scope, for example Mental Health services, or would be considered as out of scope, for example, criminal convictions.

The implementation of CIS should be a prelude to the development of clinical discipline specific standards, based on the core information standard, building on the work that has been already done for Diabetes, wound care, and nursing. This was tested in the survey, and the following services were given as areas where, potentially, standards could be developed.

- Children and young people continuing care.
- Communication and swallowing guidelines
- Community dental services
- Growth and weight standards
- Haemoglobinopathy services
- Pharmacy
- School nursing and children’s community nursing services
- Social care
- Virtual fracture clinic
- Mental health information
- Recording of safe diet consistencies for dysphagic clients, alert if AAC user
- Lymphedema services
- Dietetics
- Parkinson’s team

The development of clinical discipline specific standards was also explored with all subject matter expert interviewees and in the breakout groups at the webinars.

“One comment suggested to start with the CIS and work out what additional information is required for community health services. However, it was

unclear how the risk of duplication would be managed if all services recorded the core information and then specialist services also recorded the same information. “

“Standardised processes within the assessment are feasible (such as mobility)”

“End of Life - at the moment, just records that a respect form is in place, not where it is held.”

Data intended for planning and research purposes (secondary usage) should directly originate from point-of-care information. This approach ensures that the data utilised for broader planning and research activities is sourced directly from the information collected at the point of care. By establishing this direct link, it enhances the accuracy, relevance, and timeliness of the data used for broader analyses and research endeavours.

“Collection against operational AHP in CSDS is poor”.

“CIS seems to be a good representation of what is required for AHPs, assessments and interventions are the key and the ability to produce derived information such as RTT”.

However, it is apparent that community health services organisations require an implementation support program that tackles challenges related to people, processes, and technology.

“Many community care organisations are not able to provide adequate funding for care professionals to access technology and systems”.

“Support for implementation backed up by mandating”.

“Support for implementation needs to include training of the value of consistent information”.

There was significant support for the national definition of value and coding sets to ensure consistent data recording, this included some support for standardised assessment, such as the comprehensive geriatric assessment (CGA) and treatment escalation plans (TEP). Standardisation of templates was also supported.

“Common definition of templates would be helpful, examples would be TEP and the CGA”.

“Value sets - subsets of SNOMED CT is worthwhile but need to make sure that it works within existing systems, the standards are pretty good but need more support in implementation, need to hold system suppliers to account”.

“The definition of SNOMED CT terms for standard AHP assessments and interventions would be helpful”.

“A template supporting handover is important (this is basically a presentation of information in the system”

Patient portal emerged as a major part of the subject matter expert interviews, both as a way of providing patients, and their carers with access to their clinical information and as a conduit for the sharing of exercise plans and other elements of self-care educational materials. This is consistent with the Diabetes and Wound Care information standards.

Standardising Patient Portals presents a substantial opportunity to yield significant benefits. These portals serve as a vital platform granting patients access to their information, facilitating appointment management, and providing robust support for self-care and education in self-management practices. By establishing standardised protocols for these

portals, patients can seamlessly access and navigate essential health-related information, manage their appointments efficiently, and empower themselves through valuable self-care resources and educational materials. This standardisation would enhance the user experience and ensures consistent, high-quality support across various healthcare settings.

“There is limited access to patient portals giving patients little access to their own information, most significantly, timelines for results and links to best practice guidelines”.

“Use the NHS App and harness the expansion of the NHS App to include the About Me with the person having control.”

“Reasonable adjustments should link to the NHS app”.

“The adoption of Multi Me—an accessible online care plan over the past decade. Michael found Multi Me beneficial for reviews and meetings with professionals, allowing a comprehensive understanding of individuals' needs, communication styles, preferences, and aspirations”.

6 Conclusions

The information gathering phases of the project resulted in several messages that were consistent with the outputs of the desk-based research. These show a different priority from the original questions posed by the discovery project, however the evidence gathered has addressed those initial questions.

<p>What information standards used by community health services are universal (across healthcare UK wide) standards?</p>	<p>Technical standards and data standards are in use within community health services however there are no universal information standards in wide use.</p> <p>The 7 direct care standards identified in the research are all cross-sector standards:</p> <ul style="list-style-type: none"> • Core information standard • Personalised care and support plan • About me • End of life / Palliative and end of life care • Diabetes • Wound care • Nursing care needs <p>The core information standard, as the standard for shared care records, is becoming more widely used as shared care records are developed and implemented across England's 42 ICSs. Where shared care records exist, professionals reported significant benefits to the effectiveness and efficiency of care.</p>
<p>What information standards used by community health services are bespoke to the sector?</p>	<p>The technical and data standards as detailed above in sections 4.1.1 & 4.1.3, other than the community services dataset, are used by</p>

	<p>community services but are not specific to the sector (nor would we expect them to be).</p> <p>The community services dataset is bespoke to community health services. It defines the data for a secondary uses collection and not for sharing information for direct care.</p>
<p>What are the gaps, and would these standards be universal or bespoke?</p>	<p>The clear gap is the definition of a community health services care record.</p> <p>There is also an implementation gap for the existing standards and sharing of information between services, professionals and people which limits the effectiveness and quality of care.</p> <p>Support and guidance are required for providers and suppliers for implementation of the standards identified through the research, shared care records and/or the sharing of person information covering all areas of their health and care.</p> <p>Technical standards are required to support sharing information between systems.</p>
<p>What is the stakeholder view of prioritisation of new standards?</p>	<p>The stakeholder view of prioritisation is focussed on providing access to information from across the health and care system, so that care professionals have visibility of the care record from other organisations.</p> <p>There is support for more condition specific standards like diabetes, e.g. for other long-term conditions (a full list is in section 5).</p>

The evidence gathered also leads to the following further conclusions:

- Access to up-to-date, patient-centred information within frontline services is severely limited, directly impacting the quality of patient care.
- Community health services organisations require an implementation support program that tackles challenges related to people, processes, and technology.
- Data intended for planning and research purposes (secondary usage) should directly originate from point-of-care information wherever possible.
- The PRSB's Core Information Standard encompasses the essential data domains for supporting community health care delivery.
- Standardising Patient Portals presents a substantial opportunity to yield significant benefits. These portals serve as a vital platform granting patients access to their information, facilitating appointment management, and providing robust support for self-care and education in self-management practices.

7 Recommendations

The conclusions show that the stakeholders identified addressing the lack of shared information about a person as the key priority. This can be addressed in several ways with the main ones being:

- i. Supporting the implementation of shared care records underpinned by the core information standard, with access for community services given higher priority and/or
- ii. Supporting the development of community care record systems which can share information between community systems and with wider health and care providers/systems.

The first of these is already in progress with the 42 ICSs in England all developing shared care record systems but could benefit from further support specific for community services.

The second requires development of standards for both the content of community care records and technical standards for the sharing of information between systems. Both are identified in the conclusions.

Community health services and care covers a vast range of services with a wide range of overlapping and specific information needs. Developing a new standard would be a very large and time-consuming piece of work. However, the core information standard was developed to provide the core information about a person to support safe and effective care across any part of the health and care system. It is therefore an option for a community care record which should be considered along with the following key factors:

- The core information standard is evidence based and developed through extensive consultation across all health and care services and with professionals and people. Details are available in the final report published here: [Core Information Standard – PRSB \(theprsb.org\)](#)
- It is intended to provide the core information needed to support safe and effective care in any sector of health and care.
- It was validated as being the appropriate standard for shared care records for the community services of pharmacy, optometry, dentistry, ambulance, and community through specific work with community professionals. The report is published here: [Core Information Standard – PRSB \(theprsb.org\)](#)
- The personalised care and support plan and about me are included within the core information standard.
- Specialist record standards for nursing, wound care, diabetes, and end of life are all based on or fit with the core information standard, but extend the guidance and detail needed for those specific conditions and services.
- The discovery work showed support for developing further condition specific standards.
- The discovery work concluded that the core information standard encompasses the essential data domains for supporting community health care delivery.
- The core information standard supported by a set of specialist record standards therefore could provide the standards for the content of community care records.

The sharing of information between systems requires technical standards. A number of these already exist and have on-going development. These include:

-
- GP Connect – FHIR based technical specifications for the sharing of GP record information. These are in increasing use across the health and care system, and in particular where shared care records systems are immature.
 - UK Core FHIR specifications – These would need further extension to support the wide needs of community services. However, there are already identified needs to support the core information standard and other standards like diabetes and wound care.

Using the information above has led to the following set of recommendations to address the conclusions of this discovery work.

1. Consider supporting the implementation of shared care records, and in particular supporting the rollout and adoption in community services.
2. Consider if the core information standard, supported by a range of specialist standards, could fill the gap of a community care record standard.

If so, then develop a roadmap for the implementation of these standards in community health care services with the following phases:

- a. Adoption of the Core Information Standard, inclusive of the Personalised Care and Support Plan. This adoption serves as a crucial foundation for subsequent developments.
 - b. Inclusion of care assessments as defined in the nursing standard as the primary information standard for community health care services.
 - c. Further development and implementation support for specialised, clinical discipline-specific information standards including those identified in this report. This progression builds upon the comprehensive framework provided by the Core Information Standard, allowing for tailored standards that cater specifically to distinct clinical disciplines within the community health care domain.
 - d. Commission the extension of the UK Core FHIR standards to support the sharing of information between community health systems and with providers and their systems across health and care.
 - e. Tailored Implementation Guidance for system suppliers: Produce a series of services specific implementation guidance specifically tailored to community healthcare services, including virtual wards and physiotherapy, aiding system developers and users in effectively implementing the Core Information Standard within these services.
3. Consider encouraging the use of GP connect as an interim stage to provide broader person information where community providers have local systems without information sharing and immature shared care records.
 4. Holistic Implementation Support Package for care providers: Develop an implementation support package catering for all types of community health care service providers, that tackles the challenges related to people, processes, and technology, to ensure successful adoption of the standards selected for community record systems and shared care records.
 5. Unified Patient Engagement Portals Approach: Forge a standardised approach to patient engagement portals, extending its reach and functionality to cover the

spectrum of community healthcare services, ensuring uniformity and ease of access for patients across the board. (Note that PRSB has already been commissioned to review patient portals with findings expected in Spring 2024.)

6. Review and align the community services dataset with the standards selected for direct care and community record systems.
7. Follow up on the responses in the survey relating to development of local data sharing and standards. See page 29 for details.

Appendices

Appendix 1 Survey write-up

289 responses were collected between August and October 2023, of which 37% (n=108) were excluded on the criteria that they did not answer any of the questions, aside their occupation. After removing the exclusions, a total of 181 responses remained for analysis. 169 providers and suppliers were grouped and analysed together; the remaining 6 responses from users and carers from community health services were analysed separately.

Providers and suppliers of community health services

Most respondents (68.51%) worked in the NHS delivering community health services; the remaining were a mix of services providers within central organisations, such as NHS England, or within independent organisations. Amongst the responses, there were 3.31% (n=6) users of community health services and 3.31% (n=6) who cared for a person using community health services. The full details of the respondents can be found in table 1.

Table 1 displays the breakdown of where respondents worked (n=181).

Where respondents worked	Proportion (%)	n
Use community health services	3.31%	6
Care for a person who is using community health services	3.31%	6
Work in the NHS delivering community health services	68.51%	124
Work for an independent sector organisation delivering community health services	7.73%	14
Work for a community interest company (social enterprise) delivering community health services	3.87%	7
Deliver community health services in some other way, for example independent practitioner	3.31%	6
Work for an IT system provider of a community health services system	1.10%	2
Work for a central organisation such as NHS England or another organisation not included above	8.84%	16
TOTAL	100%	181

Furthermore, most respondents (91.02%) were from England; the remaining were from Scotland (8.38%), Wales (4.19%) and Northern Ireland (1.20%).

Answered: 167 Skipped: 14

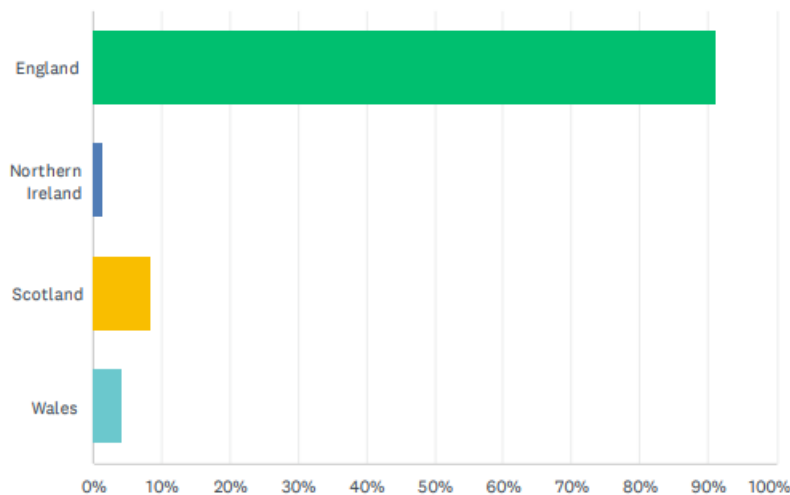


Figure 1. A bar chart displaying the distribution of respondents across England, Northern Ireland, Scotland, and Wales.

The occupations listed were varied with over half of the responses (51.48%) were from allied health professionals, NHS management and administration staff (14.79%), and specialist nurses (7.69); the full breakdown of respondents' specific occupations can be found in table 2.

Table 2 displays the breakdown of respondents' occupations (n=169).

Occupation	Proportion (%)	n
Person or patient using services	0.00%	0
Carer	1.18%	2
Volunteer	0.00%	0
Community Care Doctor	0.00%	0
Specialist Consultant	2.37%	4
General practitioner	1.18%	2
District Nurse	2.37%	4
Specialist Nurse	7.69%	13
Pharmacist	0.59%	1
Dentist	0.59%	1
Allied health professional	51.48%	87
AHP / Therapies support worker	2.37%	4
Community worker	0.00%	0
Specialist healthcare support	1.18%	2
Healthcare assistant	0.00%	0
NHS management	7.69%	13
NHS administration including data and IT professional	7.10%	12
Professional body employee	0.59%	1
Healthcare Policy	0.59%	1
IT systems suppliers/Digital Expert	1.78%	3
Other clinical (please include details of role)	0.00%	0
Other non-clinical (please include details of role)	0.00%	0

Other (please include details of role)	2.96%	5
Other (please specify)	8.28%	14
TOTAL	100%	169

The general awareness and familiarity of information standards was low, which included any knowledge about standards for information that is necessary to provide assessments, interventions, and treatments to people in receipt of care (known as direct care), such as the Core Information Standard (CIS) and those for analysis, management information and research (known as secondary uses), such as the community services data set. Over half (n=89) were not aware of standard prior to the survey, most respondents (n=71) were aware of information standard were for direct care and some (20) were aware of standards for secondary usage.

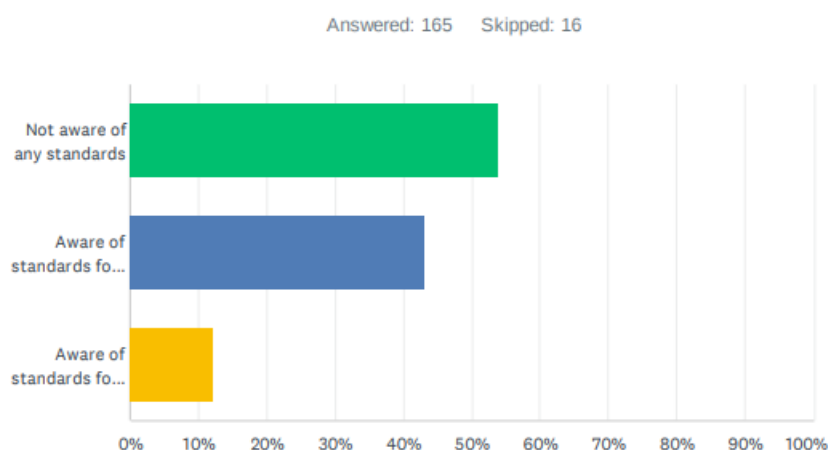


Figure 2. A bar chart displaying the general awareness of any information standards for community care prior to completing the survey; not aware of any standards (53.94%), aware of standards for direct care (43.03%) and aware of standards for secondary usage (12.12%).

Despite the low levels of awareness of information standards amongst the respondents, the consensus of a defined standard for community health services care records varied from extremely useful (46.39%), very useful (30.12%) and somewhat useful (20.48%). A minority of five responses suggested it would be not useful.

The following section details the findings of the responses regarding the PRSB Core Information Standard (CIS) data elements and further suggestions of additional data elements.

What is missing from the Core Information Standard?

The standard includes:

- Person demographics, GP practice, alerts, legal, safeguarding, professional and personal contacts, social context
- About me
- Contacts with professionals
- Admissions to and discharges from care
- Problem list, procedures, and therapies
- Referrals, future appointments, investigations and results, assessments, examination findings, observations
- Allergies and adverse reactions, risks, medications, and medical devices, vaccinations

- Care and support plan, contingency, additional supporting plans, plan and requested actions.
- End of life care plans

This is a wide-ranging set of information domains, is there anything missing from your perspective?

Over a third of respondents (n=65) skipped this question; the remaining (n=116) suggested further information domains to be included in the Core Information Standard. Many responses raised data elements that are already mapped to existing elements in the CIS. The main theme highlighted from the remaining responses were about information sharing. Some comments reported about that the feedback loop from virtual fracture clinics and trauma meetings to urgent treatment centres is currently absent, leading to a lack of information sharing. In addition, patients referred by practice nurses for dressings at these centres often do not receive formal letters, indicating a gap in communication. There is a need to incorporate linked professional contacts for better coordination. Additionally, integrating information from the third sector and social care is crucial for comprehensive care delivery. Local hospice charities, which contribute significantly to patient care, are not adequately captured within the current systems. The absence of a national system and the lack of interoperability among existing systems highlight significant challenges in information sharing across healthcare services.

Further individual comments raised the following –

- Adapt the CIS
- Care package funding streams
- Chronic disease management plans
- Community pharmacy details
- Context sensitivity
- Criminal convictions
- Mental health and physical health
- Safety and risk management
- Social care work on standards
- Standardised intervention lists
- Update the EoLC standard in the CIS to reflect the updated PEOl information standard.

Is there any other information that you would want in an information standard? How would be beneficial to the improvement of care?

Just under half of the respondents (n=87) skipped this question, with the remaining (n=94) responses highlighting the following high-level themes, which related to the challenges of accessing patient information across various healthcare settings, poor data integration and implementation of standardisation across healthcare systems.

<p>Fragmented information access</p>	<p>The current healthcare system faces significant challenges in providing holistic care, due to fragmented access to patient information. Professionals, particularly general practitioners (GPs), struggle to access critical patient data within their electronic record systems. Additionally, the separation of mental health information into a different trust poses challenges in coordinating care with mental health professionals. Consultant reports are not easily accessible due to the use of separate systems, leading to inefficiencies and hindrances in informed patient interventions.</p>
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Communication and coordination hurdles	Effective communication and coordination among healthcare professionals are hampered by limited access to crucial patient documents. Letters from various health professionals, such as consultants, are not readily available. Contact information for team members is lacking, impeding efficient collaboration. Moreover, valuable information related to inpatient admissions, end-of-life plans, admission avoidance and personalised care plans are scattered across different systems, posing challenges in providing comprehensive care and meeting patient needs.
Impact on patient care	These information access challenges have significant implications for patient care quality. Essential clinical data, including test results, scans, and reports, often remain out of reach. Speech and language therapy (SLT) notes from acute settings and shared care plans are also inaccessible, limiting the ability to deliver well-informed and patient-centred care. Inadequate access to hospital notes and assessments further compounds the problem, which underscores the urgent need for improved information sharing and system interoperability to enhance the overall healthcare experience and outcomes for patients.
Regional data sharing initiatives	One comment shared that Greater Manchester Care record (GMCR) exemplify the benefits of integrating data from various sources. These initiatives improve access to information from different healthcare systems, including mental health, social care, primary care and NHSFT, enhancing the overall efficiency of healthcare delivery.
Joined-up care and document sharing	Linking data from various sources, such as GP records, health and social care, acute trusts and emergency services is necessary for optimum patient care. Data integration is necessary for the seamless sharing of historical information and clinical reports between different healthcare services, which ensures the continuity of care and reduces the risk of harm from redundant data entry. One respondent suggested that a single, integrated record system with appropriate access for all stakeholders, including patients, would eliminate information-sharing delays and reduce patients repeatedly providing the same information, leading to a more patient-centred healthcare experience.

Would having a specific information standard be valuable?

Most respondents responded with general support for most of the care settings to have specialist information standards covering the clinical information that should be recorded when delivering care; the settings with the most support were speech and language therapy services (58.78%), long term conditions management services (48.85%), district nursing (48.85%), physiotherapy services (47.33%) and virtual wards (46.56%). The full breakdown of services can be found in Appendix 1A.

The additional comments were a combination of in favour and against individual information standards development.

In favour of standards development	There was support for specialised information standards development across health and care, with some acknowledging that it would be good in principle; however, the implementation would be overly complex and nuanced.
Against standards development	<p>Many thought it would be unhelpful to segment standards into professions, as patients in the community require holistic assessments and care.; there was emphasis on information record standards should be service-based, not profession-based.</p> <p>Furthermore, there were concerns about the documentation burden for healthcare professionals and duplication of data, which increases clinical risk and harm on patients. A few suggested that it would be useful if all services could access specialist notes and GP records without contacting and permission.</p>
Start with the implementation of the CIS.	One comment suggested to start with the CIS and work out what additional information is required for community health services. However, it was unclear how the risk of duplication would be managed if all services recorded the core information and then specialist services also recorded the same information.

Other listed areas for standards development

- Children continuing care.
- Communication and swallowing guidelines
- Community dental services
- Growth and weight standards
- Haemoglobinopathy services
- Pharmacy
- School nursing and children's community nursing services
- Social care
- Virtual fracture clinic
- Mental health information
- Recording of safe diet consistencies for dysphagic clients, alert if AAC user
- Lymphedema services
- Dietetics
- Parkinson's team

Awareness of SNOMED CT

Most respondents (86.14%) agreed that it would be useful to have standardised SNOMED CT terminology for recording clinical activity.

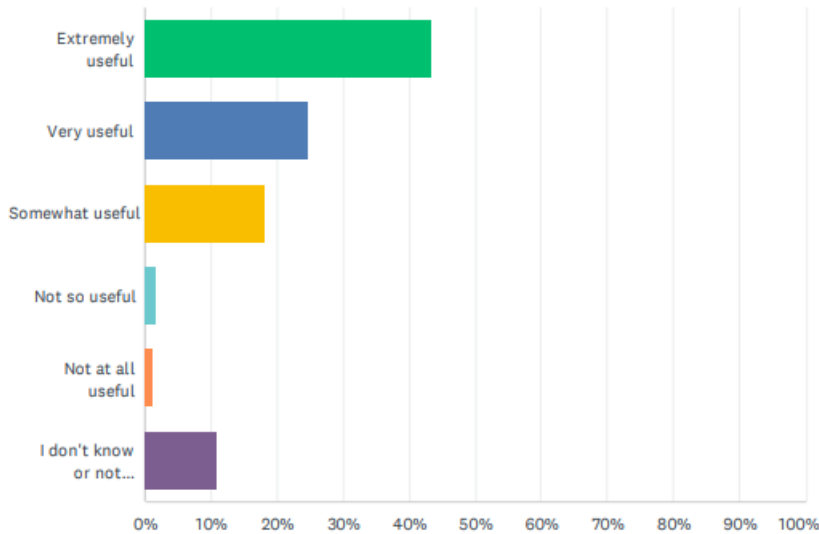


Figure 2. A bar chart displaying respondents' opinion on if it would be useful to have standardised SNOMED CT terminology for clinical activity recording; extremely useful (43.37%), very useful (24.70), somewhat useful (18.07%), not so useful (1.81%), not at all useful (1.20%) and I do not know or not applicable (10.84%).

Awareness of any local or regional work to develop community healthcare services information standards.

35% of respondents reported that they were aware of or were involved with some local or regional work to develop community health services information standards.

What are other functions that you would like your IT system to provide?

There are 85.33% of respondents who are using IT systems that record details of the consultation between care professional and person receiving care. When asked about other functions they would like in their IT systems to provide, their comments stressed the following themes:

Nationwide access, interoperability, and integration	<p>Requests for systems that can communicate and exchange information seamlessly with other healthcare systems, including primary care, acute care, social care, and various community services. Integration between different IT systems used across different settings emerged as a common need.</p> <p>Digital maturity is a concern, with one comment expressing they do not have electronic notes, which poses significant challenges for data sharing and integration.</p>
Data collection and reporting	<p>There was emphasis on efficient data collection without duplication, automatic population of forms, accurate informatics, and comprehensive reporting capability for audits, quality improvement, outcome measures, and risk assessment.</p>
Efficiency and timesaving	<p>Desire for automation was desired in data analysis, statistics, and task management to reduce the time spent on documentation, allowing healthcare professionals to focus more on patient care.</p>

	In addition, intuitive, user-friendly interfaces are desirable to mitigate the challenges related to low staffing and time pressures leading to insufficient updates in the system.
Patient engagement and access	Integration with patient portals, allowing patients to send pictures, access medical history, medications, and engage in remote consultations was expressed. 'Did not attend rates' was also suggested by one respondent.
Community-centric features and MDT collaboration and information sharing	Requirements for tailored functionalities catering to community-based care, including home-based contacts, scheduling, and support for various community services such as rehabilitation, social prescribing, and wound care assessments. Furthermore, it was stressed that real-time access to multidisciplinary notes, up-to-date contacts, and electronic notes for better collaboration and continuity of care across different healthcare settings.

Carers and users of community health services

Overall, there were six users and six carers of people who use community health services; only one respondent recorded they were from Scotland, with the remaining undisclosed. The majority (n=7) were not aware of how their care information was shared, three expressed they knew a little, and only two stated yes; one respondent stated they used KMCR.

Respondents shared their experiences and effects of when information about their care was shared. In general, a positive effect was experienced when their information was shared, as it ensured professionals were better informed of their health needs, reasonable adjustments, and medical history. Furthermore, it had a positive effect as users did not have to repeat their story. However, one commented that their patient medical history was not always up to date. Conversely, one respondent stated that their experience of shared information was usually negative, as it resulted in perceived (non-evidenced) risk and restriction. Additionally, two were unaware of the effects of their information being shared.

Users and carers expressed that an information standard must include a comprehensive array of details to facilitate tailored care for individuals within healthcare settings. This includes essential demographic information, medical history, medications, key conditions, allergies, and background details about treatments, diagnoses, and previous health problems – all shared with informed consent. Furthermore, the information standard should account for communication preferences, mobility needs, likes, and dislikes, Next of Kin details, and pertinent information allowing for necessary reasonable adjustments. The standard should prioritise objective, non-subjective information, ensuring confidentiality and adherence to clinical and information governance. Additionally, accessibility features catering to individual needs, integration with numerous services and MDTs, security measures, and the ability for different devices to seamlessly shared digital data are also critical components within an information standard. The standard must equip healthcare professionals with a holistic understanding of the individual, empowering them to deliver personalised care in line with clinical reasoning and tailored to the specific needs and preferences of the person.

Appendix 2 Subject Matter Expert Interviews

PRSB interviewed 27 subject matter experts in 19 interviews. The interviews explored the interviewees views on the use of information in the delivery of community health care services and tested priorities and potential areas of focus.

The role breakdown of the 27 interviewees was as follows.

Clinical	10
NHS Trust Digital	3
Policy	8
Social Care	1
System Supplier	5

The interviews highlighted the necessity for improved interoperability, access to patient history, and streamlined information flow across healthcare services to enhance patient care and support healthcare professionals in various disciplines. The key points raised in these interviews can be summarised as follows.

1. Information Access and Interoperability
 - Community-wide shared records are essential for accessing appointments, past medical history, and information from numerous services.
 - Access to patient history and consistent terminology in specialist treatment areas is necessary.
2. Healthcare Professional Access and Workload:
 - EPRs (Electronic Patient Record Systems) do not fully accommodate physiotherapists or single-handed professionals.
 - Implementation support, especially for agreed clinical terms, is required.
 - Scheduling in the community should consider travel time.
3. Standards and Support in Healthcare:
 - Core Information Standard (CIS) is extensive but might need clarification regarding outcomes and user experience.
 - AHPs (Allied Health Professionals) lack representation and support in current clinical systems.
4. Patient-Centric Approach and Portals:
 - Patient portals should include self-care technologies and patient-specific information, meeting GDPR standards.
 - About Me should reflect patient wishes and link to patient passports.
5. Data Sharing and Community Care Challenges:
 - Challenges exist in data sharing among independent providers and varying approaches in reporting.
 - Digital health information and system functionality need improvement in supporting care plans and communication.
6. Virtual Wards and Monitoring:
 - Virtual wards rely on varied care pathways and tasks, leading to individual clinical variability.
 - Monitoring devices provide extensive data, posing challenges in determining relevance to care processes.
7. EPMA and Medication Records:

- EPMA (Electronic Prescribing and Medicines Administration) and a single medication record are crucial for streamlined information.
8. Specialist Disciplines and Terminology:
- Inclusion of 25 specialist AHP disciplines' terminology and support for outcomes measures is crucial.
 - Clinical systems lack support for AHPs, leading to varied record-keeping practices.
9. Information Flow and Integration:
- Integration of vital signs, clinical responsibility transfer, and access to education material for specialist disciplines are needed.
 - Access to social care information and the ability to share information across patient pathways is crucial.
10. Implementation Challenges and Patient Information:
- Support for community IT services and standard definition for services like Comprehensive Geriatric Assessment (CGA) is required.
 - Patient access to information and shared care records significantly reduces time to find patient information.

The following table contains a transcription of all the statements made by the subject matter experts in the interviews. These have subsequently been categorised to allow grouping of the statements.

Interviewee Comment / Statement	Statement Grouping	Interviewee role
The 25 specialist AHP disciplines are typically not well represented in care record systems	Care record system	Policy
An AHP episode currently typically recorded as a single contact with the person rather than a series of assessments and interventions, this makes the measurement of referral to treatment time difficult	Care record system	Policy
The scope excludes mental health, however Art and Music therapists are AHPs and have the same issues as other AHPs, OT are typically part of acute care pathway	Sharing Information across pathway	Policy
CIS seems to be a good representation of what is required for AHPs, assessments and interventions are the key and the ability to produce derived information such as RTT	CIS	Policy
The definition of SNOMED CT terms for standard AHP assessment and interventions would be helpful	Terminology	Policy
AHP not well supported by current clinical systems, also infrastructure does not facilitate usage by AHP care professionals	Implementation Support	Policy
Many community care organisations are not able to provide adequate funding for care professionals to access technology and systems	Implementation Support	Policy
There is not enough adequate assessment of the care and support needs of person	Care record system	Social Care

Interviewee Comment / Statement	Statement Grouping	Interviewee role
PCSP would meet the needs by defining a clear support plan	PCSP	Social Care
Care providers are handicapped by a lack of knowledge about a person	Sharing Information across pathway	Social Care
The review of the care act, means that care providers end up having to use funds intended for one persons care to pay for care for a second person	social care	Social Care
Care providers do not get, in all cases, a full discharge letter (transfer of care) from hospital into the care service	Sharing Information across pathway	Social Care
Care needs assessment - adult needs assessment is not consistent, typically providers have their own person focussed needs assessment, often intellectual property, PCSP would seem to meet the need, but could be supported by specific guidance	Implementation Support	Social Care
There are no standards for the sharing of information between care providers	Sharing Information across pathway	Social Care
There could be a single access point for information about a person	Sharing Information across pathway	Social Care
Access to social care information would be helpful, currently care professionals have no sight of this	Sharing Information across pathway	Clinical
Sharing information (in near realtime) across the patient pathway would be helpful to support a rapid response service	Sharing Information across pathway	Clinical
Progress notes are required, these are live notes recording the clinical interventions and observations	Care record system	Clinical
Common definition of templates would be helpful, examples would be TEP and the CGA	Templates	Clinical
Email referrals are still being used, typically these are freeform rather than coded but are based on a defined informatioo set. These are then manually transcribed into patient management system	Sharing Information across pathway	Clinical

Interviewee Comment / Statement	Statement Grouping	Interviewee role
There is no access to live system when out and about, although offline access is available which provides access to the clinical record of known patients (patients on the current caseload) emergency referrals, or unplanned patients are not available.	sharing Information across pathway	Clinical
Laptops are typically too heavy and VPN is not robust when out and about (and this is in an urban area)	implementation Support	Clinical
Third sector nurses (Trinity) do not have access to any shared information, nor do they contribute to the shared care record	Sharing Information across pathway	Clinical
CIS seems to be appropriate, next of kin, progress notes and specialist plans (EoLC) needs to be available	CIS	Clinical
We should not look at community services in isolation from other care services; for example dementia services are intrinsically linked with community services, social care, and primary care	Sharing Information across pathway	Clinical
Transfer of care between care services is important, to ensure that the receiving care service have the correct level of information	Sharing Information across pathway	Clinical
Care professional access to information is required at the point of care; for example home visiting	Implementation Support	Clinical
CIS covers the requirement for patient level clinical record	CIS	Clinical
Diagnostic and condition recording is important, significant medical history should be identifiable	Care record system	Clinical
The prioritisation of a problem list should be available; there may be different views on priority	Care record system	Clinical
Having valuesets would be useful	Terminology	Clinical
Standards (and the data entry) should be kept to a minimum to reduce the clinical load	Care record system	Clinical
Uses dedicated referral form and needs to keep information confidential and secure	Sharing Information across pathway	Clinical
Test request access is important, and results, particularly viral loads which indicates whether or not medication is working	Sharing Information across pathway	Clinical
Next of Kin is a key part of demographic information	CIS	Clinical

Interviewee Comment / Statement	Statement Grouping	Interviewee role
Multi disciplinary teams require access to the Core information Standard information, and to the shared care record	CIS	Clinical
Care professional contact details needs to be available	CIS	Clinical
Standard needs to support clinical staging	Terminology	Clinical
Care professionals need to be able to access education material for specialist disciplines such as HIV	Education	Clinical
Recording the patient story is important, allowing corroboration by Next of Kin / finding	Care record system	Clinical
System should support Recording education plans, results, images assessments with supporting SNOMED CT terms	Terminology	Clinical
Using apps to support person education	Portal	Clinical
Care plans needs to be built from short term and long term goals	PCSP	Clinical
Order requesting and transfer of care	Care record system	Clinical
Workload management and the support for timesheets linked to clinical activity	Workload management	Clinical
Information needs to be presented in a way that people (care professionals and patients) want to receive it.	Portal	Clinical
There is limited access to patient portals giving patients little access to their own information, most significantly, timelines for results and links to best practice guidelines\	Portal	Clinical
GM would wish for a portal for sharing patient information and education care plans	Portal	Clinical
Support for valuesets	Terminology	Clinical
Key issues - order and requests, supportt for triage, suppor for communitication	Care record system	Clinical
If everyone is on the same system, sharing information is good, however this is often not the case across the care pathway, have to copy and paste into an email	Sharing Information across pathway	Clinical
Can access the shared care record, but can't update it, and therefore can't share progress notes about the care delivered, this results in misinterpretation	Sharing Information across pathway	Clinical

Interviewee Comment / Statement	Statement Grouping	Interviewee role
Licences for access to RIO are prohibitive in the sharing of information	Implementation Support	Clinical
Support for Triage is dependant on definition of best practice approach, which in turn is probably dependant on the standardisation of services	Best practice	Clinical
Standardised processes within the assessment is feasible (such as mobility) however a single assessment for everything not feasible. It needs to be smart to reflect the needs of the patient and the care professional (free text also allows this)	Templates	Clinical
Progress notes need to be fluid to allow care professionals to meet core standards	Care record system	Clinical
Workload management is clunky in current systems (although not sure that this can be influenced by systems)	Workload management	Clinical
Core Information Standard covers the requirement, there is nothing extra to add	CIS	Clinical
End of Life - at the moment, just records that a respect form is in place, not where it is held.	PCSP	Clinical
Patient access to information - platforms are in place to allow the sharing of exercise plans etc. Patient access should be easier and should be the full version, meeting GDPR standards.	Portal	Clinical
Communication between platforms to improve patient flow is important	Sharing Information across pathway	Clinical
Need to ensure that IT contracts reflect standards and data sets	Implementation Support	Policy
Support for community IT services is needed	Implementation Support	Policy
NHS commissions care delivered by social care	Scope	Policy
Standard definition of things like CGA is happening (iCGA) in someplaces, but not an area of focus at the moment, need someone to hold the ring on definition and ownership, this does not exist at the moment	Terminology	Policy
The core information standard is right, it just needs implementing	CIS	Policy
Intermediate care team want to do more work on terminology	Terminology	Policy
Link to social prescribing	Scope	Policy

Interviewee Comment / Statement	Statement Grouping	Interviewee role
Person access (portal) is a key part of intermediate care (although not the highest priority)	Portal	Policy
Getting the standards to frontline services in the right way is important - ISN and clinical briefings, link to DTAC	Implementation Support	Policy
A template supporting handover is important (this is basically a presentation of information in the system)	Templates	Clinical
A common assessment across services makes sense with the ability to focus on specific service needs	Implementation Support	Clinical
Core information standard covers the ground	CIS	Clinical
PCSP should be in the persons language, what they are trying to achieve	PCSP	Clinical
Things like housing status are important - protected characteristics (link to CSDS?)	Implementation Support	Clinical
Reasonable adjustments should linked to the NHS app	Portal	Clinical
Gender and preference needs to be supported	Person choice	Clinical
Shared care record access is available and will be useful to hold a community wide TEP	Sharing Information across pathway	Clinical
In discharge letter, drug use and alcohol us is only mandatory for mental health patients, not sure why this is	Implementation Support	Clinical
Having an agreed set of SNOMED CT codes would be useful	Terminology	Clinical
Extending CIS out to veterans would be useful	CIS	Clinical
Therapy outcomes measures are an important component (measures the outcomes) 9 point scale in a number of domains, this allows tracking across an episode of care	Outcome	Clinical
Therapy work involves assessment, intervention and outcomes	Implementation Support	Clinical
CIS - missing outcomes and the episode list	CIS	Clinical
User experience is missing	Person choice	Clinical
Multimedia content (audio and photos) needs to be included, the need to look at any limitation about file size etc.	CIS	Clinical

Interviewee Comment / Statement	Statement Grouping	Interviewee role
Need to differentiate between confirmed and suspected diagnosis	Terminology	Clinical
Using AI to support clinical practice	AI	Clinical
EPMA and a single medication record would be valuable information	Sharing Information across pathway	Clinical
Interoperability and access to a community wide shared record	Sharing Information across pathway	Clinical
Need to know about appointments and information from other services	Sharing Information across pathway	Clinical
Access to past medical history	Sharing Information across pathway	Clinical
Implementation support for specialist areas of treatment (consistent terminology)	Implementation Support	Clinical
Patient centric view of which services are current	Portal	Clinical
Digital health information (and system functionality) needs to be improved	Implementation Support	Supplier
Access to care plans is limited	PCSP	Supplier
There is no standard definition for virtual wards, due to the personalisation of care and this being bespoke to individual patients, . Recording of vital signs is defined by clinical specification guidance. However, this is dependent on the needs of the patient which generate varied care pathways and tasks, which are generally set by the consultant.	Implementation Support	Supplier

Interviewee Comment / Statement	Statement Grouping	Interviewee role
<p>The information about the Personalised care and support plan focuses on monitoring deterioration and intervention recording. This is bespoke to the patient and includes the escalation plan.</p> <p>e.g. Alarm is triggered and picked up by the nurses, who can refer. They then can select the correct outcome.</p> <p>This particular method enables assessment of the benefits of the particular alarm and can indicate if the prevention was time sensitive.</p> <p>In addition, they have the capability to nudge behaviour via a 2-way messaging video conference; this overcomes privacy and confidentiality within a traditional ward, and protects the time of the healthcare provider, whilst being beneficial to the patient.</p>	PCSP	Supplier
Individual clinical variability is a result of the parameters bespoke to patients needs.	Care record system	Supplier
Terminology varies across care settings and socioeconomic class and there is a lack of high-level definitions.	Terminology	Supplier
A defined set of questions for clinicians will support the individual pathways to be tied down.	Templates	Supplier
Accountability/ responsibility of the community team needs to be clearer.	General	Supplier
An MDT approach to ensure the standardised information is relevant and consistent to varied health practices.	Sharing Information across pathway	Supplier
Standard approach to documentation is beneficial; however, this is heavily dependent on the level of expertise and experience of suppliers. E.g. Automated information should be uploaded to a dashboard from the provider, and the patient should not be able to tamper with their results.	Templates	Supplier
Current crop of EPRS do not work well for physios. They tend to record AHP contacts in the context of other care professionals, but typically do not record what interventions were performed and the impact / effect of these interventions	CIS	Policy
Scheduling of work in the community needs to make allowance for travel time	Implementation Support	Policy
Single handed professionals (30% of AHPs) do not typically have access to EPRs or shared care records	Sharing Information across pathway	Policy

Interviewee Comment / Statement	Statement Grouping	Interviewee role
PCSP makes sense	PCSP	Policy
Collection against operational AHP in CSDS is poor	Secondary usage	Policy
We should be enabling greater self-care using technology	Portal	Policy
Implementation support especially through the provision of agreed clinical terms would be beneficial	Implementation Support	Policy
Difficult to exclude social care from scope	Scope	Digital
AboutMe should include patient wishes, link to the patient passport	Aboutme	Digital
Prescribing functionality is key, as is the move to patient online services for self-care	Care record system	Digital
Cares/NoK needs to be explicit	Care record system	Digital
Need to consume items such as acute discharge medications, and ED end of episode notes	Care record system	Digital
Key areas for inclusion in record needs to include, alerts, including safeguarding alerts, patient wishes, risk stratification.	Aboutme	Digital
Shared care records need to include flag that person is under the care of another clinical team, specifically this is an issue when the patient is on a virtual ward	Sharing Information across pathway	Digital
Having consistency of definition of value sets would be valuable, this should extend to templates and coding ,For example admission avoidance / managed discharge	Terminology	Digital
Virtual wards have a lead provider and typically will be managed through the clinical systems of this lead provider, very often these are Acute Trusts	Sharing Information across pathway	Digital
Remote monitoring systems are typically not connected to patient management / clinical systems	Care record system	Digital
System needs to be available at the pt of care (this can give an infrastructure challenge	Implementation Support	Digital

Interviewee Comment / Statement	Statement Grouping	Interviewee role
Security around systems, when you go mobile potentially lose smartcards (as these are only needed for spine access). New system entrants are not biometric / multifactor	Security	Digital
Need to reference DTAC and enforcement of this in report	Implementation Support	Digital
Integration of vital signs is important for virtual wards but does not need to be covered in more detailed here because medical devices definitions address this	Care record system	Supplier
Outcome and goals are important	PCSP	Supplier
Core information standard is extremely comprehensive and covers the space, no apparent deficiencies	CIS	Supplier
In bound flows from community are developing, there is some immaturity to support technical flows from some organisations, hospices given as an example	Sharing Information across pathway	Supplier
Coding is key, not every provider is as consistent with coding Shared Care records typically take what they can get	Terminology	Supplier
questionnaire data is largely dependance on symptoms, can be unstructured and therefore more of a challenge	Terminology	Supplier
Assessments can be typically unstructured, therefore it is difficult to have a standard, given there is variety of practice	Terminology	Supplier
Standard structure for a care plan is needed	PCSP	Supplier
Virtual wards focussed on treating people who otherwise would be in hospital, therefore it is analogous to acute care - consultant led	virtual wards	Policy
Virtual wards share data, to support the immediate care purposes, e.g. vital signs and shared care records	Sharing Information across pathway	Policy
Pathway for virtual ward admission, intervention, discharge, length of stay is 14 days or less	virtual wards	Policy
Virtual wards require the layering of functions, such as prescribing, lab tests etc. from multiple organisations	virtual wards	Policy

Interviewee Comment / Statement	Statement Grouping	Interviewee role
Transfer of clinical responsibility is a key issue for virtual wards, link to transfer of care standard	virtual wards	Policy
Monitoring devices can provided a mass of data, need to think about over monitoring and determining what is relevant to care processes	virtual wards	Policy
Virtual wards typically provided by multiple organisations, hence the need to share information between the MDT	Sharing Information across pathway	Policy
The scope is a missed opportunity the scope of community services is broad and many of the issues across into social care funded services	Scope	Policy
Need to think through prioritisation as well as just capturing everything	Implementation Support	Policy
Data submission at national level from independent providers is only a subset of what providers do, there is variation at a local level, we don't want to make the national set a superset. Priorisation is important	Implementation Support	Policy
ICS's (trust) are asking providers to report in different ways, consistency would be valuable and improve the quality of returns and the care record	Implementation Support	Policy
Accessing the GP record is the most common use of shared care records, also summary views, medicines, adverse reactions, problems & allergies	Sharing Information across pathway	Supplier
Having a shared care record, significantly reduces the amount of time that is needed to find information about patients	Sharing Information across pathway	Supplier

Appendix 3 Service user testimonies

The main findings across the interviews with users and carers of community healthcare services include:

- Service users felt that the community health services did have the appropriate information; however, this was centrally driven by the user informing the service providers independently, rather than being readily available and accessible online. This also led to many users and carers stating that repetition of information was common. One user expressed that their services did not have the right information at all, due to the rarity of their conditions and provided leaflets to inform health services the right information so they could receive the right care.
- Overall, most users felt that the community health services could be improved; both users and carers advocated for the integration and implementation of Multi me⁶ across all services, as it would empower and reinstate individuals to have control of their own care whilst allowing professionals to have comprehensive understanding of individuals' needs, communication styles, preferences, and aspirations.

Older people and dementia

Service user A attends East London Day service, which supports elderly people and people with Dementia and Alzheimer's twice a week and believes that community health services possessed the necessary information for appropriate qualification. However, there are some concerns about the accuracy of health-related information, noting that it might not be entirely precise due to potential misinformation. Their extensive experience using numerous services suggests that the information provided is accurate only if they have directly communicated it to the service providers.

Service user B attends East London Day Service, which supports elderly people and people with Dementia and Alzheimer's once per week, she suffers from the rare disease Multiple System Atrophy (MSA), expressed frustration over the lack of accurate information within health services due to the obscurity of her condition. To address this gap, she provides a leaflet from the MSA Association to supply necessary information. She emphasises the need for improved communication among health services, advocating for collaboration between departments rather than individualised approaches. Gloria highlights the challenge of having to repeatedly explain her condition because of the healthcare providers' failure to comprehend it, resulting in a lack of accurate information sharing about her specific needs and situation.

Service user C attends East London Day Service, which supports elderly people and people with Dementia and Alzheimer's and engaged with various community health services including consultants, general practitioners (GPs), and dentists; he expressed satisfaction with the availability of accurate information across these healthcare providers. Gerry appreciated having comprehensive information regarding treatments and expressed overall positivity about his experience with these services. Despite his positive encounter, Gerry acknowledged that there is room for continuous improvement within these community health services.

Service user D attends East London Day Service, which supports elderly people and people with Dementia and Alzheimer's, and she acknowledged that once community services

⁶ Multi Me is a self-advocacy and person-centred planning platform for individuals with disabilities and their circle of people that support them in their daily lives.
<https://www.multime.com/>

understand her needs and what is available, the experience becomes positive. However, she noted that her daughter manages the coordination of these services and encounters different queries from various people involved. Once the service providers become familiar with her requirements, the process became more straightforward. Overall, Patricia believes there is always room for improvement in these services.

Service user E with various community health services including doctors, opticians, and dentists; she expressed contentment with the accuracy of information available within these services. She expressed that these services had comprehensive details about their frequency of visits, locations, and patterns of usage. Additionally, she appreciated that if any information is lacking, the service providers promptly identify and address these gaps. Overall, she appeared to have encountered no issues in accessing these community health services.

Physical disability

Service user F accesses wheelchair services, occupational therapy, and community nursing. She highlighted issues with certain health services not possessing accurate information about her, resulting in difficulties accessing appropriate care and a lack of information sharing.

"Some health services aren't good because they keep sending me to the poly clinic, which doesn't have any hoists. As a wheelchair user who cannot get up or walk, it is a problem. They do not have the right information at all. They get everything wrong, especially at the medical centre. Whether they have hoists or not, considering I can't walk, seems like common sense."

"I haven't been to the doctors for a long time. Nurses come to cut my nails and dressings, and they have the right information. Wheelchair services are unreliable; they arrive at the wrong time and once went to my old house. I'm getting a new wheelchair, but I'm not happy about it."

"During meetings with the occupational therapist (OT) and nurses, I have to repeat myself. I have been waiting for equipment for two weeks, but my OT listened to me. Services don't share the right information, especially hospitals and doctors - it needs sorting out."

"Something like Facebook or a messaging service would make me so happy because I could easily contact them. I am not happy; the doctors have sent me three times from the centre to clinics that do not have hoists, so I cannot get my tests done. I've been waiting for nearly four years now for my chest."

Service user G expressed dissatisfaction with wheelchair services, stating they only attend when the wheelchair is broken without conducting regular check-ups. While acknowledging that these services possess the correct information, he believed no additional information is necessary. However, he highlighted a lack of understanding regarding how information is shared within these services and express a refusal to provide further details about themselves. He approved of Multime, a communication platform, suggesting it could prevent the need for repeated explanations in the future. He seemed content with the available information but are concerned about the lack of knowledge regarding information sharing protocols within the community health services.

Service user H attends community services three days a week and relies on wheelchair services for mobility and expressed dissatisfaction with the extended waiting period for wheelchair service repairs, which started in March, causing inconvenience, and preventing access to day services. As a wheelchair user, she emphasised the crucial role their

wheelchair plays in daily activities such as shopping and movement, highlighting its essentiality for everyday life and work. During the wheelchair breakdown, they had to work from home, heavily relying on the wheelchair for their daily routine. She suggested that wheelchair services understand the significance of their chairs and how they function. She proposed a platform called "wiki" or "Multime" that contains comprehensive information about her chair usage and lifestyle, believing it would benefit healthcare professionals like doctors and nurses if they had access to this information. This would help healthcare services better understand the individual's needs and lifestyle when providing care and services.

Learning disability and autism

Service user I receives community physiotherapy at home to assess his leg and arm mobility; he confirmed that the physiotherapists possess accurate information about his condition, documenting details regarding the physiotherapy sessions and arms. Overall, he described the experience as satisfactory, citing the friendly nature of the physiotherapists. He, also, noted that the health professionals access information online and, during the last interaction, spoke to Irfan's brother. Despite having another upcoming meeting, he appreciated that the services have not cancelled any previous appointments.

Service user J, who receives community physiotherapy and resides with her mum and twin sister, confirmed that the healthcare providers possess accurate information about her. However, she expressed dissatisfaction, mentioning the absence of details about her emotional state. Although the community health services inquired during sessions, they seemed unaware of the information beforehand. She acknowledged that the services are conscious of her dietary requirements but is uncertain about how they acquired this information. She noted that they documented details regarding her communication methods, which indicated an attempt to understand her needs and preferences in this regard. Overall, while the providers have accurate basic information, there seems to be a gap in understanding Julie's emotional state prior to appointments.

Service user K, who resides at home with her family and attends a Day service, expressed the challenges of being housebound and the negative impact of waiting for a wheelchair battery. She highlighted her interaction with wheelchair services, mentioning that they possessed the necessary information to provide her with support. They required details like her name, address, preferences, and the need for a hoist. She shared her frustration with waiting several months for a new wheelchair. She expressed a desire for quicker responses from services, emphasising that if they had acted sooner, they would have understood her situation better and potentially avoided the prolonged isolation she experienced, which was further prolonged due a lift breaking down. She advocated for the use of Multi Me to facilitate improved and timely communication, suggesting that this could prevent long waiting times and enhance the overall support provided by community health services.

Service user L, who utilises wheelchair and physiotherapy services, shared her experiences with these community health services. She expressed that sometimes they possessed the correct information about her needs, which alleviated the need for repetitive explanations during appointments. However, she remained unsure if these services have access to her surgical and operational history. One significant concern she raised is her discomfort with physical touch, highlighting the importance of having this information known to service providers beforehand. She acknowledged occasional feelings of anxiety and prefers to communicate her concerns directly during appointments. Overall, while she appreciated not having to repeat herself, she underscored the importance of having her surgery history and discomfort with physical contact acknowledged and accessed by community health services prior to appointments for a smoother and more comfortable experience.

Service user M, who resides alone in a flat and attends a Day Centre, shared her experience regarding physiotherapy following stent surgery. In her account, she expressed satisfaction with the community health services, stating that they actively listened to her needs and provided adequate support during her physiotherapy sessions. She felt comfortable communicating her requirements, indicating a positive experience with the healthcare providers' responsiveness and supportiveness in addressing her needs post-stent surgery.

Service user N, who lives independently and attends a Day service, interacts with chiropody, diabetes services, and learning disability services. She highlighted difficulties primarily related to the referral process within these community health services, in particular chiropody. She expressed frustration with attempts to secure a referral for her foot check-ups, crucial due to her diabetes. Despite her eligibility, she reported encountering obstacles when seeking these services. She mentioned persistently requesting a nurse to make a referral for her, which indicated her efforts in trying to access necessary care. However, Ross expressed that the foot clinic did not listen to her needs and repeatedly denied her requests, which created barriers to essential healthcare services.

Support staff and carers

Support staff/ carer A, working as a support worker at a Day service, shared insights into facilitating individuals' access to community health services. She described her experience as generally positive, aiding people in their daily activities, notably regarding wheelchair assistance. However, Zelia pointed out challenges within the system, particularly regarding the absence of professionals or adequate personnel to fulfil certain roles. She noted a significant issue of information passing between different entities but a lack of individuals available to carry out necessary tasks. She highlighted that they effectively communicate the needs of the individuals they support. However, she expressed frustration over frequent cancellations, which disrupted the continuity of care for the service users. She appreciated the effectiveness of platforms like Multi Me for communication purposes. Furthermore, she stressed the need for social workers to have better resources, including increased staffing and improved communication channels, to ensure smoother and more consistent support for individuals accessing community health services.

Support staff/ carer B, a community support worker, and a parent of a daughter with sickle cell disease, shared her combined professional and first-hand experiences with community health services. She reflected on her diverse work experiences supporting various individuals. Esther noted discrepancies in the availability of accurate information within the services, particularly during service initiation. She cited instances where inadequate communication led to issues such as incorrectly delivered equipment, which caused inconvenience and delays for service users, who then must wait for prolonged periods for replacements. She suggested the implementation of a comprehensive system accessible to all involved parties, allowing visibility into the entire process and appointment scheduling. She advocated for a system that enables easy communication for appointment confirmations, especially beneficial for individuals with communication challenges, ensuring doctors have the necessary information. Regarding her daughter's sickle cell disease, Esther narrated distressing experiences of her daughter attending multiple appointments for a scheduled surgical procedure, only to find that the booking was not in place. This situation causes her daughter stress, both mentally and physically, leading to unnecessary pain. She proposed the development of a simplified and easily comprehensible "passport" system that accommodated the needs of individuals who might struggle with complex information, envisioning a feasible solution that would benefit the individuals they work with.

Support staff/ carer C, a senior team leader at a Day Service supporting elderly individuals, including those with Dementia and Alzheimer's, discussed various challenges within

community health services and assessments. She explained the daily process of receiving referrals from social workers, assessing support plan needs, and encountering conflicts in information provided. She described instances where discrepancies arose between family reports and social worker assessments, particularly regarding mobility support needs that necessitate home visits and potential Occupational Therapy (OT) assessments. These procedures required time-consuming referrals, which affected service intake and jeopardised individuals' health and safety needs. Tracey highlighted issues faced by individuals with specialised conditions such as Alzheimer's, diabetes, and their related dental and GP reviews. She noted that when individuals attend these professional appointments, they often missed attending the services, which led to a lack of first-hand professional information available to service providers. Expressing concerns about inadequate information sharing, Tracey emphasises the importance of implementing platforms like Multi Me for uniform information access across involved parties. She advocated for greater integration of information to avoid repeated explanations and enable better collaboration between service providers. She stressed the need for improved communication and information sharing among professionals and service providers, suggesting the use of Multi Me as a solution to unify information and enhance understanding of individuals' needs across various community health services.

Support staff/ carer D, a community support worker at Elderberries Day Service, specialising in assisting elderly individuals, particularly those with Dementia, Alzheimer's, and complex needs such as autism, shared the challenges related to joint working and collaboration within community health services. He addressed difficulties concerning hospital and dental appointments for nonverbal individuals, noting a lack of pertinent information available. Randy explained the need to proactively search for missing elements and information by contacting social workers (SW) and family members to ensure comprehensive care. He advocated for collaboration and working together using platforms like Multi Me, stressing the importance of sharing information about individuals' needs across different health service providers. He highlighted the significance of improved communication and information sharing systems to bridge gaps and ensure individuals receive comprehensive care, especially for those who may have difficulty communicating their needs verbally.

Support staff/ carer E, a senior support worker with extensive experience aiding disabled individuals across various adult social care settings, shared insights into the impact of multimedia tools on self-advocacy within care services and the importance of information sharing. He mentioned the use of person-centred planning, initially in paper format and more recently, the adoption of Multi Me—an accessible online care plan over the past decade. Michael found Multi Me beneficial for reviews and meetings with professionals, allowing a comprehensive understanding of individuals' needs, communication styles, preferences, and aspirations. He emphasised the positive impact of Multi Me in combating isolation, as it empowered individuals to take control of their lives and advocate for themselves effectively. Furthermore, Michael expressed efforts in promoting the use of Multi Me, acknowledging its potential to facilitate better communication, organisation, and empowerment within the community health services domain. He highlighted issues stemming from insufficient information sharing across services, leading to repetitive explanations of individuals' needs. He underscored the negative impact of communication lapses and delays in resolving essential matters, such as repairs to equipment like wheelchairs, which significantly affect individuals' lives, isolating them until resolution.

Appendix 4 Webinar Write-up

Three webinars were used to validate and verify the findings and gaps from the earlier stages of the project. Two of the webinars were organised by PRSB and were open to all stakeholders, including front-line community care professionals for the in-scope services, as well as CIOs, CCIOs, and CNIOs from community providers and community care EPR system suppliers. The third session was part of the NHS England Digital Community Health Service Forum. All three of the webinars and included breakout groups that were asked to address the following three points:

- Will shared care records (supported by the Core Information Standard) cover all the information that is necessary to provide high quality community health services?
- Could patient portals or other functionality, benefit from a standards definition?
- What implementation support would you require, for example would it be helpful to define community health services specific value sets against things like assessments and procedures?

A write up of the comments and observations made by participants is included below. There was clear support for the need for a comprehensive, standardised, and accessible patient centred information shared across the care pathway (and across organisational boundaries). Systems need to prioritise patient needs, interoperability, and usability for healthcare professionals. However, here was concern that, whilst the core information standard covers all the information that is necessary to support community health services, it is large and there is the potential to over burden care professionals.

The comments and observations can be summarised into the following key messages.

1. Information Sharing and Capture:

Capture comprehensive details for people in receipt of community care services, including special needs and communication requirements.

- Improve information sharing between hospitals and community care to ensure continuity of care.

2. Patient Care Plans and Portals:

- Develop patient-centric care plans accessible through portals with multimedia and patient-specific details.
- Ensure patient consent, language accessibility, and inclusion of images.

3. Standards and Interoperability:

- Standardise information across healthcare systems to ensure seamless integration and sharing.
- Address challenges such as data ownership and interoperability issues.

4. Implementation Challenges and Support:

- Provide support for implementing standards, training, data security, and ownership clarification.
- Simplify information recording, prioritising a narrative approach over tick-box methods.

5. Patient-Centric Approaches:

- Use patient-centred language and prioritise role-specific, relevant information for healthcare professionals.
- Emphasise prioritisation of information based on distinct roles and responsibilities.

6. Patient Portals and Access to Information:

- Ensure patient portals offer relevant information, reduce repetition, and maintain data security.

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- Enable access to pertinent information for healthcare professionals while ensuring ease of use.
7. Care Record Consistency and Management:
- Ensure consistency in care records, manage complex plans, define ownership, and maintain updated and accurate information.
 - Avoid overwhelming healthcare professionals with excessive standards while ensuring compliance.
8. Technological Integration and Tools:
- Utilise national tools such as the NHS App for interoperability and provide user-friendly interfaces across different devices.
 - Focus on the practicalities of implementing systems and tools to facilitate smoother workflows.

The following table contains a transcription of all the comments and observations made by the webinar attendees during the plenary feedback sessions. These have subsequently been categorised to allow grouping of the statements.

Plenary Comments & Observations	Categorisation
Communication needs from the patient reflect reasonable adjustments and must be available to care professionals involved in the care of the patient	Reasonable Adjustments
Implementation support for core information standard is needed - this should include support to implement and to understand the standard	Implementation Support
Images are an important part of the care record but don't underestimate the issues about consent, these shouldn't be constrained by organisational boundaries	Images
Standards are already in place, however the operational detail of this needs to be looked at interoperability not in place. Need to strengthen the "About Me" standard	Aboutme
Use the NHS App and harness the expansion of the NHS App to include the About Me with the person having control	Portal
The implementation of systems is limiting the sharing of data, needs to be a national drive of this	Sharing Information across pathway
Alerts needs to be shared. There is a disconnect between the way that clinical systems develop	Sharing Information across pathway
Who becomes the owner of shared records	Ownership
Better integration into social care, digital social care record and minimum operational data set needs to be looked with consistent coding	Sharing Information across pathway
Open EHR - concept of a single filing cabinet	Sharing Information across pathway
Reasonable adjustments - including communication needs	reasonable Adjustments
Cross over between children and adults	Children's information
Support for implementation needs to include training of the value of consistent information	Implementation Support
Images form an important part of the care record	Images
Sharing should not be constrained by trust/organisational or postcode boundaries	Sharing Information across pathway
Core information does have the right content and therefore a further standard is not needed	CIS
Clear language and single point of access is necessary for patient portals	Portal

Plenary Comments & Observations	Categorisation
Use of resources, standard templates would help support implementation , timeframe	Templates
CIS is comprehensive and provides what we need	CIS
Standard for patient portal is a good idea, however needs to link to nice and other guidance	Portal
Resources are a key issue ownership of templates needs to be defined and information elements need to be data / time stamped allowomng care professionals focus on relevant information	Implementation Support
CIS covers the requirement, but it asks clinicians to swallow a whale, limited information flowing electonoically between organisations, copy and paste still being used	CIS
CIS contains a huge amount of data Implementation of must does, should haves and nice to haves	Overloading care professionals
Focus on things like Patients expectation for their care and Treatment Escalation Plans (TEP)	Templates
Systems should not necessarily be patient centred, the access that staff get should be staff focussed (user centred design), views for different care professionals should be relevant to their role	Overloading care professionals
Don't underestimate the culture change, massive pick lists don't work need to focus on a small set of information	Implementation Support
Standards are needed, must do, need to do should be specified	Policy
Frustration about interoperability Mandation is needed, for example a GP can refuse to share records from their systems	Policy
Support for implementation backed up by mandation	Implementation Support
One set of standards wouldn't support all patient portals	Portal
Communiuty care works across the whole spectrum touching primary, acute, social etc. Gaps about the implementation of standards such as PCSP	Sharing Information across pathway
Clinicians need to be able to filter to focus on the critical information, particularly in an urgent situation	Overloading care professionals
Borders need to be considered, training in record keeping standards is required, there are different ways oif working between care professionas	Sharing Information across pathway
Yes CIS would work, however, data items are distributed across multiple systems and therefore bringing together a single assessment is difficult	CIS
Potential opportunity for a single portal however how is it built in a way that is meaningful	Portal

Plenary Comments & Observations	Categorisation
Valuesets - subsets of SNOMED CT is worthwhile but need to make sure that it works within existing systems, the standards are pretty good but need more support in implementation, need to hold system suppliers to account	Implementation Support
Technical issues with structured information and data sources, which increase risk.	architecture
CIS is very large which is not realistic, need to focus in on the key information, referrals, reasonable adjustments	CIS
NHS App should be the patient portal, or at least the point of access to other portals	Portal
TEP need to be accessible for care professionals in any Trust	Example
Discharge summaries and TEPS need to be standardised, this may be an implementation / compliance area	Sharing Information across pathway

The final table contains a transcription of all the comments and observations made by the webinar attendees during the breakout groups feedback session, these have also been categorised to allow grouping of the statements.

Breakout group Comments & Observations	Categorisation
Children details need to be captured, same level of information for children as for adults	Children's information
Children with special educational needs, information will be needed by the education system as well as social care and the health system	Children's information
need to flag up communication needs, specifically what means people use to communicate, or if people have difficulty with communication.	Reasonable Adjustments
When people go in to hospital and are then discharged back to community, the community team have access to very little information about the hospital episode of care	Sharing Information across pathway
Movement between acute and community is akin to transfer of care	Sharing Information across pathway
Treatment in the community needs to represent the patient choices, particularly in EoL however is wider than this	Person choice
Sharing of information across the patient pathway should include the plan as well as problems, treatment, and procedures	Sharing Information across pathway
Plan should include trigger	PCSP
CIS provides what is needed	CIS
PSCP provide what is needed, it just needs implementing	PCSP
Need support with the definitions and codings of assessments	Terminology
Support with waiting lists , and individual service line resources	Resources
Should link with professional bodies to support implementation and awareness of standards	Implementation Support
A virtual MDT where everyone has access to the same information would be valuable	Sharing Information across pathway
Need to consider how to bring together multiple care plans into an overarching care plan for an individual	Sharing Information across pathway
Patient portal to support self care, patient specific treatment plans and support for things like exercising	Portal
Important to include photographs and digital images (with appropriate consent)	Images
Level of consent	Consent
Always consider what information needs to be recorded to support the delivery of care	Sharing Information across pathway

Some patients will have complex care and support plans, who is responsible for this plan, who owns and maintains	PCSP
CIS is a comprehensive list, how does it relate to the universal care plan (coordinate my care) - need to have common definitions to allow the sharing of care plans between different systems	CIS
Care plans contributed to (or developed) by any care professionals	PCSP
CIS covers the requirement	CIS
Encompass in NI, is it consistent with the Core Information Standard	Example
Black Pear and Cyder in Somerset	Example
Resources and ownership are the major challenges. Need to ensure that it is maintained. Having multiple platforms poses a challenge but common templates could help	Implementation Support
Content would suffice and people need to have access to it	CIS
Knowing what the provenance of an information set is valid, and what information is still current	Provenance
Too many pilots and standards already, we do not need more	Implementation Support
Need to avoid overwhelming care professionals	Overloading care professionals
What does ownership mean, who is leading on a set of information	Ownership
Moving away tick box recording of information to a more narrative approach, care professionals need to be clinically led not data led	Overloading care professionals
For patient portals information needs to be in a language that is accessible to patients (ie not use jargon or term that may not be understood)	Portal
Patient portal should be specific not generic, in that it needs to present information that is relevant to the service that the patient is receiving	Portal
Portals should provide the information that is relevant to the patient and the services that they are receiving	Portal
Information should be relevant	Overloading care professionals
Should be able to collate information from multiple sources to prevent the patient having to repeat information	Sharing Information across pathway
Standards should have a review period	Provenance

Should it be a single PCSP, a standard can be interpreted in many ways, we need to be clear that a PCSP is personal not bound by organisational (or system) boundaries	PCSP
CIS covers everything, many IT provides meet this already, but there is a gap allowing care professionals to access it on the go in a secure way	CIS
Referrals need to be included	Sharing Information across pathway
Whilst most systems meet the CIS / PCSP definition we need to look beyond the data item level to an architecture that allows a single PCSP made up of many parts (SAP)	PCSP
NHS commissioned care includes many providers including voluntary sector and care homes and therefore the community care record or PCSP needs to include information and plans from these other recommendations	PCSP
Are MH services included in the care record, but they need to be part of a single PCSP and care record - leading to the Book of Jo	Sharing Information across pathway
NEMS is a key part of the architecture, we need to build on top	architecture
Implementation support in the agreement PCSP	Implementation Support
Subsets of SNOMED CT is not a good idea, however, you need a good browser to support the care professional	Terminology
Need to link to Wayfinder and other programmes of work	architecture
We need to be tighter about the compliance	Implementation Support
Systems need to support cares by reducing the amount of repetition	Sharing Information across pathway
Systems must talk to each other -	Sharing Information across pathway
OpenEhr - patient system what a patient record should hold, PKB is the best example of this	Example
Aboutme is the patient information, how do we access it, how do we share this, should be linked into CIS to say where it is held	Aboutme
Red book as a analogy, could this be an app	Example
Wales is going paper lite - only 3m people so is the barrier scale	Example
Care portal in lincolnshire but patient portal is not there yet, however are still barriers to sharing, which requires clinician time to unravel	Portal
Patient held information is important	Portal

however needs to underpinned by a good shared care record. We have the systems and standards, need support in implementation	Implementation Support
Multidisciplinary perspective of shared records is important	Sharing Information across pathway
Link up the about me to the reasonable adjustmenmts	Reasonable Adjustments
The NHS App expansion is key - need to tie into this, about me and reasonable adjustments need to be included	Example
Patients need choice about where their about me information is held, this should link through to the NHS App	Portal
Flagging that a care plan exists, -Anticipatory care plan in exist	PCSP
Single NHS care record	Example
Ambulance service has special message forms, paper in the home for EoLC - lions tube in the fridge, paper processes are the safest	Example
Photos should included	Images
Anticipatory care plan - patient led	PCSP
Clinicians need to be able to filter to focus on the critical information, particularly in an urgent situation	Overloading care professionals
Information should be prioritised based on role	Overloading care professionals
CIS needs to be covered by an ISN, which will be backed up by FHIR	CIS
NHS information should be kept secure, GCHQ should be looking after it, with central definition	Security
Who is the data controller this poses challenges with the current range of systems / data sources	Ownership
The information that we want in emergency is the same regardless of the speciality, patient preferences are a key part of this	Sharing Information across pathway
How does access to about me work in practice, the practicalities are as important as the data	Aboutme
Not all views should patient centred, clinical pertinent views are essential, should the building of standard views (templates) be part of the standard	Overloading care professionals
Should alerts be prioritised	Care record system

Seeing the right information is important to get the right clinical outcome, this partly depends on the capabilities of clinicians	Sharing Information across pathway
Role based access is necessary, need a clinically focussed view, there are issues with interoperability	Security
Interoperability issues are the bane of our existence, one trust has a vast range of services and therefore standardisation is a challenge, limited contact with neighbouring trusts, communication between trusts relies on written communication and (in some cases) the patient acting as the postie	Sharing Information across pathway
Commercial considerations are also a barrier	Commercial
No recognised standard in terms of record keeping, broad agreement in terms of SNOMED CT, however written notes are variable, ranging from single line referrals with acronyms, to paragraphs of text with images, its dependant on the recorder	Terminology
Implementation issues - training of care professionals is necessary, consistent recording etc, need to define clinical governance issues	Implementation Support
NE London have defined a interoperability strategy, need to differentiate between patient management systems and EPRs	Example
Universal care plan in London	Example
Core information standard is extremely long, who would be expected to fill it in, we need to ensure that it is not burdensome	Overloading care professionals
Build templates for specific service types, however a lot of the information already resides elsewhere, this needs to be harvested from these systems, whole piece about interoperability and how you get the data into the front line systems.	Templates
Standards need to drive the sharing of information, grabbing it from elsewhere, this is a technical and a governance challenge, also needs to be based on common definitions. The governance issue shouldn't be an issue, provided it is being shared for direct care	Sharing Information across pathway
Sharing information needs to be dynamic, for example if a person is in ED, the district nurse needs to know about this when they see the person at home, later that day	Sharing Information across pathway
Who owns data that is shared	Consent
Data quality and efficiency is important, if the load is onerous, quality will be patchy	Overloading care professionals
Compatibility with care homes (data needs to be accessible at locations that the person is)	Sharing Information across pathway
CIS, there are things that have to be done, for example identifying the person, GPO etc. then you need to prioritise information, for	CIS

example Alerts on where the benefit is, for example in virtual wards, if a person attends has been in A&E the fact that the person is also on the virtual ward is important	
Tactical fix for example CIS show the art of the possible	CIS
How does the rehab plan relate to the PCSP, professionals need to know that the plan is there	PCSP
Should be more seamless in the sharing of information, for example care homes have nothing from a ward about a person that they are receiving, this impacting care. The key items should be identified to support transfer of care	Sharing Information across pathway
Data and information is present, but not available, for example, an acute will have a discharge note, but this is not shared to a shared care record, providers do what they want (prioritise) but not in a consistent way.	Sharing Information across pathway
Care plans exist that do not conform to the PCSP standard and could be shared in a nonstandard way	PCSP
Need to make shared care records more consistent	Terminology
Need tighter integration than just embedding	Implementation Support
Building a standard for patient portals	Portal
Standard for tasking and shared care plans	Portal
RIO / KMCR in Kent and Medway, can transfer and refer patients	Example
Suppliers have said that they understand the need but are worried that if they do not have standard definition, they will end up being pulled in multiple directions, need the standard definition of tasks	Terminology
Noth Middlesex also on RIO have had issues with agreeing template, there is an issue in defining templates in the system , in a way that is sympathetic to the way that clinicians work	Templates
Full fat RIO does not work on mobile devices, need tablet specific forms for smaller devices, which then. Integrate back into the main EPR	Example
Need to have the right devices that work in the environment	Example
Is there coordination between national IT providers	Policy
Still a paper-based operation	Example
There are standards for sharing information, but support for implementation, and mechanism for sharing is necessary	Implementation Support
Shared care record is only showing a small element of the overall patient record, and do not necessarily include the PCSP level	PCSP
Need systems that communicate with each other	Sharing Information across pathway

Mandating is needed, for example a GP can refuse to share records from their systems	Policy
Understands the issues that have been raised	Policy
What is the minimum that needs to be mandated	Overloading care professionals
Core standard may vary by service line	CIS
Will become a feed to federated data platform and faster data flows	Sharing Information across pathway
Need to have a conversation about what should be mandated	Policy
To make systems interoperate, we need to tighten up on the obligation to share data, for example GP Practice should be mandated to share data	Sharing Information across pathway
We should be using the national tools such as ERS to improve workflow	Policy
Workflow needs to include a proactive look at alerts and, for example reasonable adjustments to improve patient experience	Sharing Information across pathway
About me page should be completed	Aboutme
The amount of information coming through as a referral is a big ask	Overloading care professionals
What is the perspective that we are looking at? You are not going to need all this information for all services, need to define the subsets necessary for specific services and functions (such as referrals)	Sharing Information across pathway
Reasonable adjustments - is being added to national care record, therefore need to link to this	reasonable Adjustments
If you have multiple sources of information, which is the source of truth	Sharing Information across pathway
Are shared care records useful, typically these have a very limited dataset, and sharing into and from community systems (TPP) is a problem. Data sources are not structured and the information is not pulled together (separate tabs from each feed)	Sharing Information across pathway
Only inpatient stays and appointments in Cornwall, gone from read-only, to being the source of TEP	Example
Should be using the spine for things like TEP	Example
NHS App should be the patient portal, or at least the point of access to other portals	Portal

NHS E need to think about patient flows., need to have definitions about EPRs and portals etc

Sharing Information across pathway

Appendix 5 PRSB Core Information Standard

The PRSB Core Information Standard (PRSB CIS) focussed on what a care professional would need from a shared care record to inform professional decision making. The Core Information Standard defines a set of information that can potentially be shared between systems in different sites and settings, among professionals and people using services.

The PRSB CIS encompasses all care settings across health and social care and includes things the individual wants their care professional to know about them as well as their legal status.

The standard aligns with many other published PRSB standards including maternity, healthy child, and the community pharmacy standard. The standard also includes updates from the social care programme such as vital About me content – the information a person wants to share with health and care professionals.

The CIS was developed from research and evidence gathering and through extensive consultation with health and care staff across health and social care. It was also specifically validated for community pharmacy, optometry, dentistry, ambulance, and community services. The reports detailing this are available at [Core Information Standard – PRSB \(theprsb.org\)](https://theprsb.org).

Given the purpose of the PRSB CIS, its focus on shared care records and broad applicability, it is possible that one or more of the community health care services may decide that the PRSB CIS already meets their needs.

The 38 sections of the standard, and the ability to expand detail, is shown on the Web at: <https://prsb2.vercel.app/page/core-information-standard> the explanation of the different sections is maintained in the implementation guide: <https://theprsb.org/wp-content/uploads/2021/09/Core-Information-Standard-Implementation-Guidance-v2.0.docx>



Sections of the PRSB Core Information Standard (1)

Section Heading (of the PRSB CIS)	Explanation
Personal demographics	A person's details, NHS numbers and contact information.
GP details	Details of the person's GP.
About me	Information a person wishes people caring or supporting them to know about them.
Individual requirements	A person's individual requirements, for example reasonable adjustments, mobility needs or impairments
Alerts	Conveys a warning of important, time sensitive, and/or safety information, for example an alert to a care professional that someone is unsteady on their feet.
Legal information	Legal information for example mental capacity assessment, deprivation of liberty safeguards, lasting power of attorney
Safeguarding	Concerns that a person is at risk of abuse, harm or neglect.
Professional contacts	Professionals with significant interaction with a person for example the name of the relevant social worker or key worker.
Personal contacts	People with significant interaction with a person for example an informal carer, next of kin or a friend or a relative.
Participation in research	Participation in research study/trial and/or drug/intervention.

Sections of the PRSB Core Information Standard (2)

Section Heading (of the PRSB CIS)	Explanation
Referral information	The details of a person's referrals.
Contact with professionals	Details of encounters a person has had with health and care professionals.
Admission details	Details of the person's admission to hospital (recorded at the point at which they were admitted).
Discharge details	Details of the person's discharge from hospital (recorded at the point at which they were discharged).
Future appointments	Scheduled future appointments with health and care professionals.
Vaccinations	Records of vaccinations
Problem list	A summary of the problems that require investigation or treatment and that other professionals should be aware of
Procedures and therapies	Details of any procedures performed. Includes both psychological and medical therapies and procedures (e.g. cognitive behaviour therapy, hip replacement).
Social context	The social setting in which the person lives, such as their household, occupational history, and lifestyle factors.

Sections of the PRSB Core Information Standard (3)

Section Heading (of the PRSB CIS)	Explanation
Services and care	The services and care provided for the person.
Primary support reason	Typically from Social Care data and National Reporting on Short and Long Term Services (SALT) for example Learning disability support, mental health support, physical support
Family history	Details of relevant illness in family relations deemed to be significant to the care or health of the person, including mental illness and suicide, genetic information etc.
Investigations results	Details of diagnostic test results.
Investigations required	Details of diagnostic tests that have been requested.
Examination findings	Details of clinical findings from examinations.
Pregnancy status	If the person is pregnant
Assessments	Details of a person's health and social care assessments. Information about the assessment that has taken place and the outcome of the assessment.
Formulation	Personal meaning and origins of a person's difficulties.

Sections of the PRSB Core Information Standard (4)

Section Heading (of the PRSB CIS)	Explanation
Risks	Identified risks of harm to the person or others.
Allergies and adverse reactions	Description of a person's allergic reactions.
Medications and medical devices	Details of a person's prescribed and over the counter drugs e.g. dose and frequency. Details of the support a person needs to take the medication. Details of any medical devices the person may have.
Equipment and adaptations	Details of equipment/asset (or modifications) that the Local Authority has provided to the patient.
Plan and requested actions	The details of planned investigations, procedures and treatment, and whether this plan has been agreed with the person or their legitimate representative.
End of life care	Details of end of life preferences the person has specified e.g. advance statement, preferred place of care, preferred place of death.
Documents (including correspondence and images)	Specifically, a person's relevant medical correspondence, charts and imaging.

Sections of the PRSB Core Information Standard (Personalised Care and Support Plan)

Section Heading	Explanation
Care and support plan	Details of a care and support plan covers what is most important for a person to reach their personal and health related goals..
Contingency / safety plans	Details of a plan of what should be done if the individual's condition or other circumstances get worse.
Additional support plans	Details of an additional/specific care plan (for example wound management, behaviour support plan, dietetics), which the individual and care professional consider should be shared with others providing care and support to the individual.
