Professional
Record
Standards
Body

Better records
for better care

CORE INFORMATION STANDARD

SURVEY RESULTS AND ANALYSIS

JULY 2019

Acknowledgements

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

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Revision History

Version	Date	Summary of Changes
1.0	31/05/19	Publication version

Reviewers

This document was reviewed by the following people:

Reviewer name	Title / Responsibility
PRSB assurance committee	PRSB assurance committee
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This document was approved by the following:

Name	Date	Version
Project Board	26/06/19	0.6
PRSB Assurance Committee	19/06/19	0.6

Contents

1 Introduction

This is an appendix to the final report for the core information standard.

The online survey was one part of the overall consultation approach in the development of the core information standard and came after detailed work on specific topic areas and a national workshop on the entire standard. The survey ran from 1 April 2019 to 1 May 2019. Feedback from the consultation prior to the survey (webinars, citizen's focus group and a national workshop) was used in the design of the survey. The survey was aimed at frontline care professionals, people who use services and their carers and systems suppliers. This report includes the results and analysis of the survey. The findings from the survey were used to inform the development of core information standard. In total 1010 individuals participated in the survey.

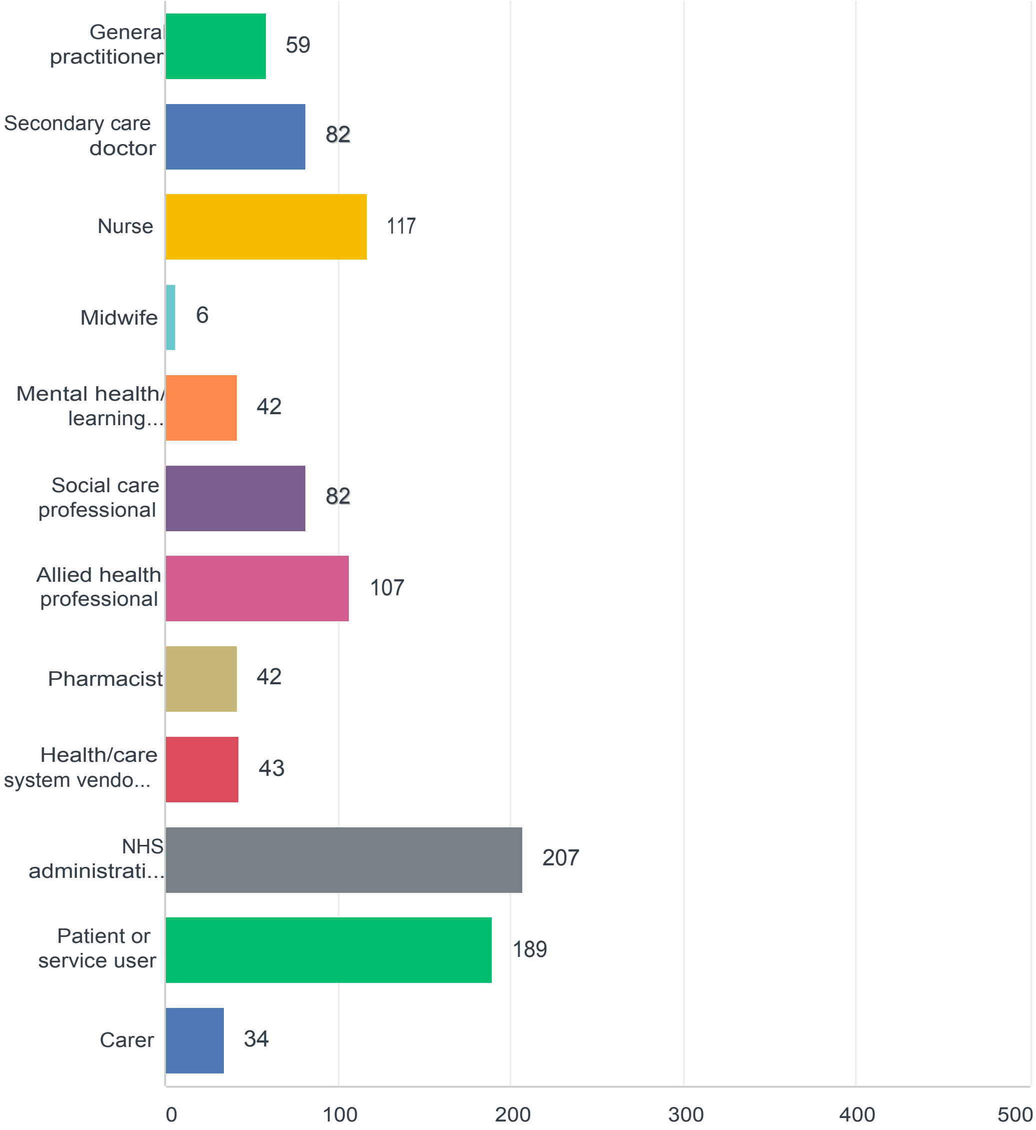
The survey was sent to 1325 individuals, including advisory board representatives and key contacts to distribute across their networks. Additionally, it was distributed to the 708 subscribers of the PRSB newsletter, the 413 stakeholders who we identified as possible attendees for the webinars and workshops, and past workshop attendees. The survey was featured in a number of publications such as the NHS Improvement provider bulletin, Digital Health Intelligence, NHS England CCG bulletin, NHSE Informed and NHSE Intouch, on professional platforms such as Ryver and with other groups including the Pharmacy Digital Forum and Scottish Children's Cancer and Leukaemia Group members. The survey was also tweeted, with 325 re-tweets and more than 81,000 impressions.

The survey was also publicised through the chief social and adult and children's social care directors, the care provider alliance representing up to 2 million working in domiciliary care and care homes, system suppliers, LHCR teams and patient groups such as the Wellcome Trust, Understanding Patient Data, National Voices representing 140 charities and the Patient Information Forum representing 300+ charities.

The first two questions of the survey identified respondents’ roles and the settings in which they work; these are shown below:

1.1 Q1. Please tell us which of the following best matches your role. Please tick the appropriate job description and add more detail in the box provided below about your specific role.

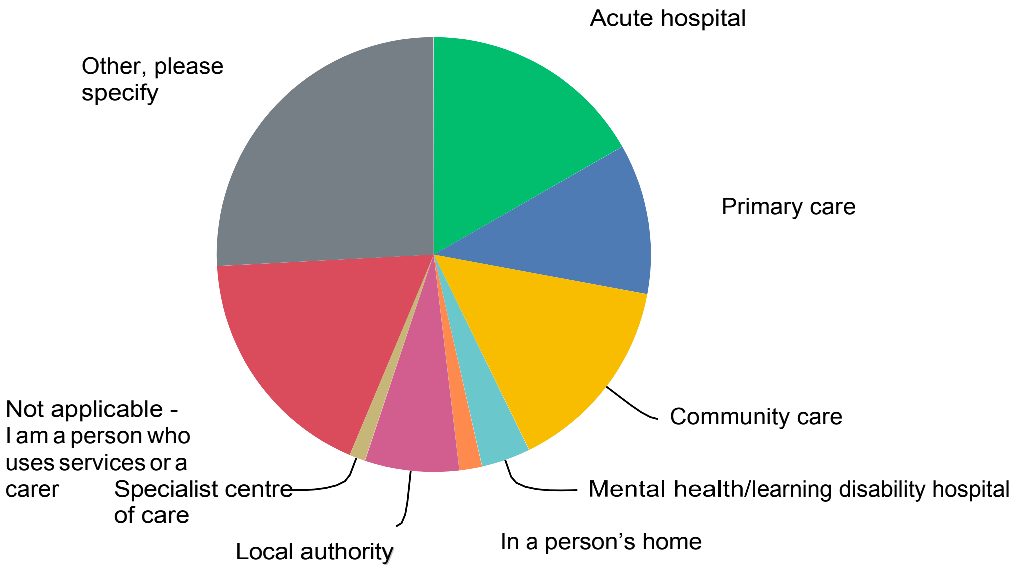
(Answered: 1,010, Skipped: 0)



ANSWER CHOICES	RESPONSES	
General practitioner	5.84%	59
Secondary care doctor	8.12%	82
Nurse	11.58%	117
Midwife	0.59%	6
Mental health/ learning disability professional	4.16%	42
Social care professional	8.12%	82
Allied health professional	10.59%	107
Pharmacist	4.16%	42
Health/care system vendor or developer	4.26%	43
NHS administration/ management	20.50%	207
Patient or service user	18.71%	189
Carer	3.37%	34
TOTAL		1,010

1.2 Q2. Please describe the setting in which you work.

Answered: 1,010 Skipped: 0



ANSWER CHOICES	RESPONSES	
Acute hospital	16.73%	169
Primary care	11.19%	113
Community care	14.85%	150
Mental health/ learning disability hospital	3.66%	37
In a person's home	1.68%	17
Residential care home	0.00%	0
Local authority	7.03%	71
Specialist centre of care	1.19%	12
Not applicable - I am a person who uses services or a carer	17.82%	180
Other, please specify	25.84%	261
TOTAL		1,010

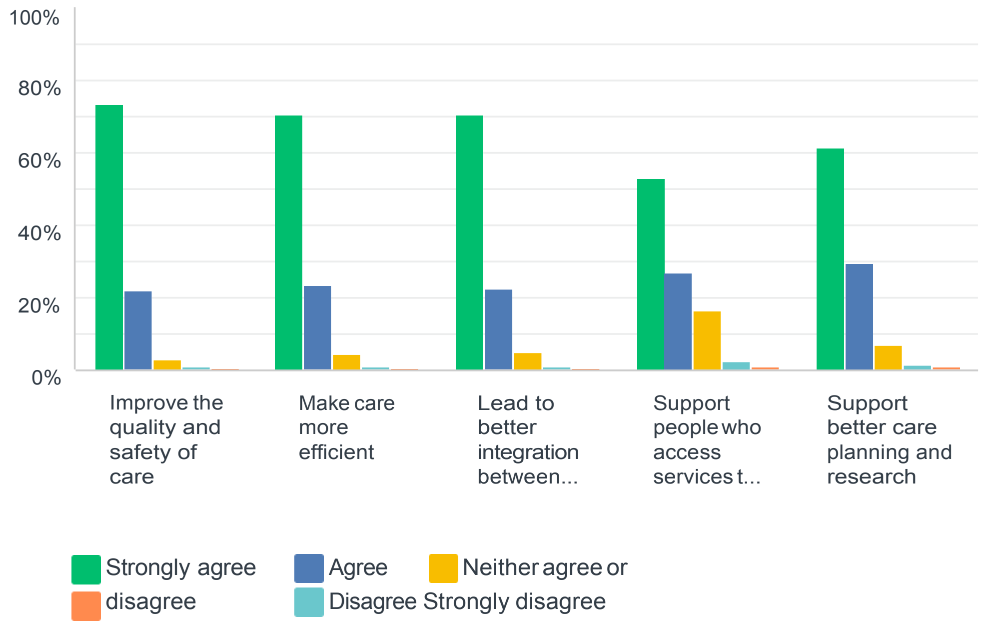
2 Question analysis

2.1 Introduction

Each question is shown in the following sections together with quantitative statistics and key themes that emerged from qualitative analysis on the comments (where available).

2.2 Q3. Do you agree that sharing core information will bring these benefits?

Answered: 1,010 Skipped: 0



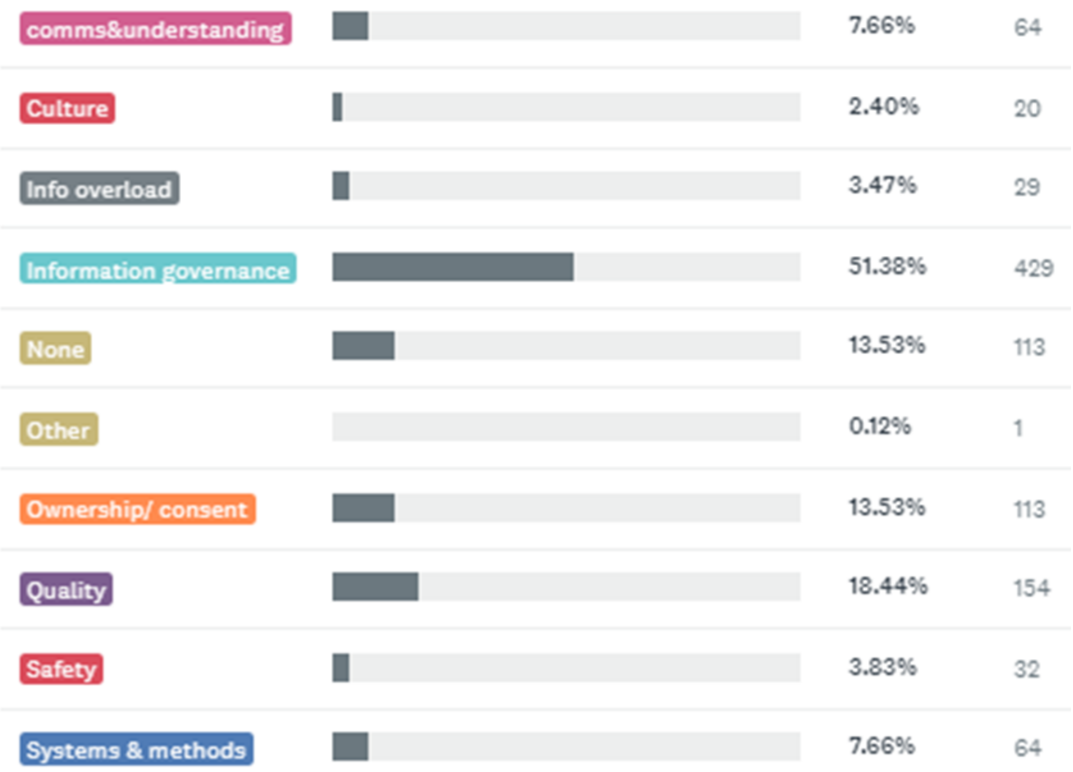
	STRONGLY AGREE	AGREE	NEITHER AGREE OR DISAGREE	DISAGREE	STRONGLY DISAGREE	TOTAL	WEIGHTED AVERAGE
Improve the quality and safety of care	73.56% 743	21.88% 221	2.97% 30	0.89% 9	0.69% 7	1,010	1.33
Make care more efficient	70.40% 711	23.37% 236	4.46% 45	1.09% 11	0.69% 7	1,010	1.38
Lead to better integration between health and care services	70.69% 714	22.48% 227	5.05% 51	1.09% 11	0.69% 7	1,010	1.39
Support people who access services to take more control and manage their own care	52.87% 534	27.13% 274	16.34% 165	2.48% 25	1.19% 12	1,010	1.72
Support better care planning and research	61.49% 621	29.41% 297	6.83% 69	1.39% 14	0.89% 9	1,010	1.51

- More than 90% or respondents think sharing core information would improve quality, safety, efficiency, integration and planning and research. More than 80% of respondents believe sharing core information will support people who access services to take more control and manage their own care.
- None of the doctors, nurses and social care professionals that took part in the survey expressed strong disagreement that sharing information would bring benefits.
- Allied health professionals were less sure of the benefits that sharing of core information would bring across the board with a small percentage strongly disagreeing that it would improve quality, safety, efficiency, integration, support for people and planning and research.
- Carers and pharmacists were more confident, none disagreed or strongly disagreed that sharing core information would have the various listed benefits.
- People who use services were least sure about the potential benefits, with 6.03 % disagreeing that sharing core information will be beneficial and 10.05% stating they were unsure that sharing would deliver the listed benefits.

2.3 Q4. What concerns do you have about sharing core information?

Answered: 835 Skipped: 175

The concerns raised were grouped into themes. The chart below shows how often they were mentioned as a percentage of the total comments.



Key:

- Comms and understanding – health literacy/ accessibility, public engagement – purpose/benefits of information sharing etc.
- Culture – working practice, habits, clinician priorities, lack of change etc.
- Info overload – too much to read given clinicians' heavy workload, important information buried etc.
- Information governance – security, unauthorised access, GDPR, selling of data for profit, data leaks etc.
- Ownership/consent – informed consent, patient held, patient granted access, information belongs to the patient
- Quality – accuracy, inconsistencies, error, interpretation, out of date etc.
- Safety – confidentiality, safeguarding, sensitive information
- Systems and methods – IT, investment, lack of interoperability, system crashes, breadth of consultation, information model etc.

- Information governance was the most commonly cited concern overall and from each group of respondents when analysing their responses individually. There was fairly widespread concern regarding the sharing of data with wider industry for commercial exploitation, in particular health and holiday insurance companies and financial institutions. 36 respondents directly mentioned concerns about the sale of data. A small number of respondents commented that the rigours of GDPR and IG were a barrier to successfully sharing information (or were used as such). People who use services were the group that most frequently expressed concerns over information governance, with 61% of these respondents mentioning information governance concerns in their responses.
- The second most cited concern for GPs, pharmacists, vendors, people who use services and their carers was the quality of the information shared. How to identify the source, accuracy and timeliness of the data came up numerous times.
- The second biggest concern for nurses and midwives was systems and methods.
- The second biggest concern for social care professionals was ownership and consent.
- Doctors, midwives, social care and mental health professionals were interestingly less concerned with information overload.

A number of themes emerged from the qualitative analysis:

Information Governance and Security

A common theme was expressions of concern about:

- Information governance
- GDPR
- Cyber security including security breaches, unauthorised access, and data being hacked

Data Quality

Concerns were also raised about potential data quality issues including:

- How to identify the 'source' of data, how to determine the accuracy of data if held in different systems, and how updates would be refreshed
- How to ensure the timeliness of data and ensure it was the most up to date
- What if data is missing?
- Who is accountable for the accuracy of data?
- Who has entered the data?
- Individual's ability to point out inaccuracies and have them put right
- Concern was expressed that if patients were uploading data, e.g. blood pressure, how could its accuracy be assured?

Data ownership

A number of respondents were keen to emphasise that the individual, not the system, owned the data.

Information access

Several common themes emerged regarding information access:

- access should be on a role-based 'need to know' basis
- individuals should have the right to restrict access to information
- individuals should have access to all their information
- individuals should be informed about who has access to their information, and who has actually viewed it
- concerns were raised regarding accessibility to information for those with learning disabilities, dementia and older people
- the requirement to have safeguards to prevent healthcare professionals accessing patient information for whom they are not clinically responsible.
- Clarification of GDPR rules. What about in an emergency situation? Breaking the glass?

Consent

Several common themes emerged regarding consent to share information:

- How will consent to share data be approached? If patients have the right to restrict access to information, then consent needs to be considered flexibly and not as 'all or nothing'
- If patients do not trust or have confidence in the system, they may withhold consent, or withhold information, either of which could compromise safety
- Capacity for consent
- Potential for patients to be coerced into sharing data that they do not wish to
- Will multiple healthcare professionals all have to ask for explicit consent from a patient?

Effective communications and engagement

- A common theme was that there was a need for effective communications and engagement to gain public and patient confidence and trust in sharing information.

'About me'

- The comment was made that 'about me' should be the cornerstone, and that a person-centred approach should be adopted.
- Conversely, the comment was made that the approach should be to prioritise clinical benefits over patient access and self-management.

Retaining clinical context

- Several respondents identified that data without context may at best be meaningless, and at worst may compromise safety. There is a need for provenance and for supporting information.

Documents Transfer

- The requirement to be able to transfer documents is considered key and is linked with context.

Information overload

- A common view was expressed that there was a fear of information overload if important information is not made easily accessible.
- There was also a concern raised that critical information might be missing.

Meaningful for people and professionals

- The view was expressed that information must be meaningful for people who use services as well as professionals. Health literacy will vary, and complex terminology will not be understood by some people who use services.
- A need was also identified to train professionals in how to populate information to avoid confusion.

What is core information?

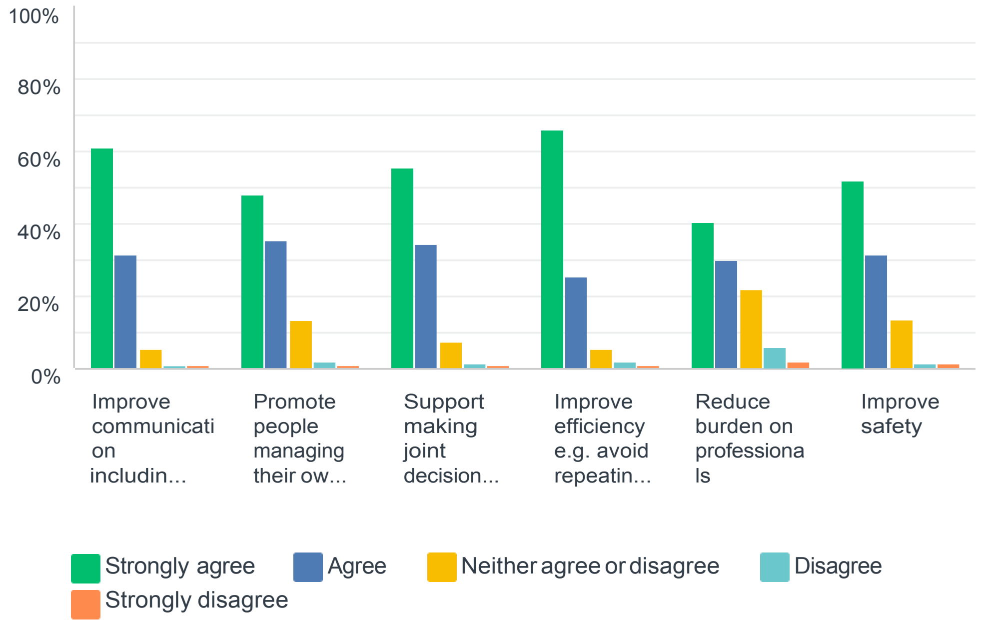
- There was confusion over what should be core information.
- The view was expressed that this definition of core information was aspiring to be comprehensive and not just essential information.

"Patients/people receiving care understanding what they are sharing and for what purpose and can easily and securely express and change their preferences on how their data is used. • Ensuring security and appropriateness of access • Willingness of health partners to share. • Understanding of GDPR 'vs' patient confidentiality. • Making sure it is easy for frontline staff to access the information- any additional barriers will prevent staff from accessing the information. • Driving information system development from a purely technical / digital strategy perspective not addressing care outcomes, will reduce shared data use and access to shared information. • Ability to fund the necessary skills training, care pathway developments, integrations and system supplier costs. • Data sharing is a people issue; it won't just be delivered by new software and hardware. • Silo working in care organisations focusing purely on internal operational needs creates inconsistent data standards and interoperability between key parts of the care economy" ***(Local authority – commissioning and social care professional)***

"Integration will be slow and impeded by lack of interoperability between systems, IG requirements, cost and training time to implement" ***(Pharmacist, acute hospital)***

2.4 Q5. Which of the following benefits would people who use services get from contributing to the information held in their health and care records? For example recording their needs, values and preferences or measurements they have taken such as blood pressure.

Answered: 1,010 Skipped: 0



	STRONGLY AGREE	AGREE	NEITHER AGREE OR DISAGREE	DISAGREE	STRONGLY DISAGREE	TOTAL	WEIGHTED AVERAGE
Improve communication including the timeliness of information sharing e.g. sharing test results	60.95% 615	31.71% 320	5.25% 53	0.99% 10	1.09% 11	1,009	1.50
Promote people managing their own care	47.87% 483	35.68% 360	13.28% 134	1.98% 20	1.19% 12	1,009	1.73
Support making joint decisions with professionals about their care	55.74% 563	34.26% 346	7.72% 78	1.29% 13	0.99% 10	1,010	1.58
Improve efficiency e.g. avoid repeating information	66.14% 668	25.54% 258	5.54% 56	1.78% 18	0.99% 10	1,010	1.46
Reduce burden on professionals	40.38% 407	29.86% 301	22.02% 222	5.75% 58	1.98% 20	1,008	1.99
Improve safety	51.98% 524	31.55% 318	13.49% 136	1.69% 17	1.29% 13	1,008	1.69

- A large majority of respondents agree that people who use services would benefit from contributing to the information held in their health and care records.
- Front line staff, people who use services and their carers, vendors and administrators were least convinced that people contributing to their records would reduce the burden on professionals.
- Social care, mental health and learning disability professionals and people who use services were most convinced that people contributing to their own record would benefit them positively and that it would support joint decision making. Whereas vendors were less convinced that people contributing to their record would encourage joint decision making.
- Allied health professionals and social care professionals were least convinced that people contributing to their record would improve safety, but nurses and pharmacists thought the opposite, that people's contribution would ensure safety.

154 people left comments

A number of themes emerged from the qualitative analysis:

Whole person view

- This will facilitate a more holistic view of the individual and how they perceive their situation, needs and wants. The person's voice will be heard. The focus will be on the person not the pathway.
- Some people did express the view that they didn't see how it would actually help them manage their own care.

Benefits realisation

- Significant concerns were raised that potential benefits would not be realised if the development and implementation of the core information standard was not done well. It is not just about the information but about changing the business model and providing adequate training.

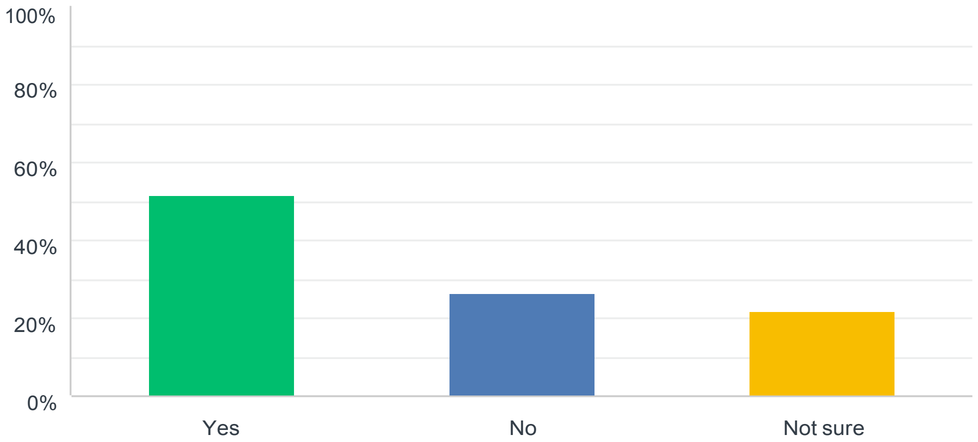
Other potential benefits

Several other potential benefits were identified including:

- Reverse the rise in treatment of those who have expressed the wish for no further treatment
- Reduction in prescribing errors
- Allow some care to be moved outside of the acute setting to the home e.g. routine out-patient appointments
- Use data for research and analysis to improve public health

2.5 Q6. Can you see any issues arising as a result of people who use services contributing to and sharing their information?

Answered: 984 Skipped: 26



ANSWER CHOICES	RESPONSES	
Yes	51.73%	509
No	26.32%	259
Not sure	21.95%	216
TOTAL		984

- Carers and midwives were the only groups from which a minority of respondents thought that people contributing to their own record would cause issues. Most carers said they were unsure, and midwives were split, with 33.33% responding yes, no and not sure.
- Allied health professionals, patients, pharmacists, doctors and GPs foresaw the most issues with people contributing to their record. GPs were the most worried with 82.76% expecting issues to arise as a result of people using services contributing to and sharing their information.

573 people left comments

A number of themes emerged from the qualitative analysis:

Data quality / accuracy

Quite extensive concern about how the quality and accuracy of data entered by individuals could be validated. Concerns were expressed about:

- Capacity to enter accurate data - in particular regarding mental health issues, learning difficulties etc. Need to assess person’s competence.
- Person entering incorrect information which might result in a practitioner making an incorrect judgement.
- Information may be out of date.
- Particular concerns over patients entering medical data e.g. blood pressure incorrectly whether by accident or design. In the former, where does clinical responsibility lie? In the latter, for example, a patient may think they will get a better response if they were to exaggerate. Will clinicians need to validate data entered by patients?

Information which may cause anxiety

- Concerns were expressed that it may cause undue anxiety to patients were they to access information which had not been shared with them by their healthcare professional, e.g. test results which were outside the norm.

Inequality of access

- Concern was raised about those who might not have access to computers, e.g. the elderly, or those who might have learning difficulties.

Information sharing - what next?

- Concerns were expressed that this would increase workload as, if information is shared, someone has to read it.
- In addition, if a person enters data, is a professional expected to respond? This might range from a person stating that they had suicidal thoughts, to a delay in seeking help as the person had entered information which they might think would elicit a response, to the 'worried well' providing excessive information.

Vulnerable users

- Concerns were raised about at risk or vulnerable patients being manipulated by others, in particular safeguarding issues where the person causing the risk might access information about the at risk person.

Health and social literacy

- The use of complex terms, terms with specific meaning and acronyms etc. in both health and social care may be problematic for people accessing their information and this needs to be addressed as an implementation issue.

"A lot of information is open to interpretation by the reader, so the need for further explanation might arise and introduce delay, confusion or waste. However, I believe that the probable benefits outweigh the possible risks. Also, as a patient, I have seen how interpretation of information has led to poor communication among healthcare professionals. The patient/carer can act as "glue" when given access to their own information. And as much as professionals believe that they have communicated fully with patients, the truth is that patients often are not given full information about themselves. Some patients, of course, don't want this. I certainly do." *(Person using services)*

"A concern that when I contribute to my record - add something - that HCPs won't read it or action it. Currently I use the online prescriptions service, but my practice never reads any of the comments or questions I put in the free text box. They've told me that they don't have the time to read them." *(Person using services)*

"However big transformation needed. GPs in particular seem to be worried about capacity to read information and act on it. We need to be clear with patient / citizen which of their information we will act upon as soon as we receive it v that we will act upon at their next appointment when we see them. We also need to put good informing in place.. not ask for consent. (Commercial lead / digital consultant shared care record)

2.7 Q7. Sections of the core information standard. Here is a summary of the key information included in the core information standard. Please rate how important this information is to you. Think about what information it would be helpful to know that you can't currently access.

Answered: 1,008 Skipped: 2

- Overall most participants ranked all the information categories important and helpful to have access to.
- People who use services ranked each field highly.
- Respondents thought medications and allergies followed by 'about me' and problems and diagnosis were most important and placed the least emphasis on sharing participation in research and developmental skills.
- Nurses, social care and allied health professionals specified safeguarding as one of the things they would find most important and helpful to access. GPs, secondary care doctors and people who use services all listed medications and allergies and 'about me' as most important.

No qualitative analysis was undertaken as this question was establishing the adjudged importance of each section.

2.8 Q8. What, if anything, is missing from the list of core information?

Answered: 361 Skipped: 649

In response to the question on what is missing from the information model a number of respondents focused on functionality they would expect to see when accessing the information such as:

- Signposting to relevant information or services
- Weighting of importance of information for particular roles
- Identification of frequency of visits (e.g. to A&E)
- Links between information e.g. legal documents and plans or link between problems and encounters
- An audit trail of who had accessed what information
- Ability to set sharing preferences
- A record of complaints

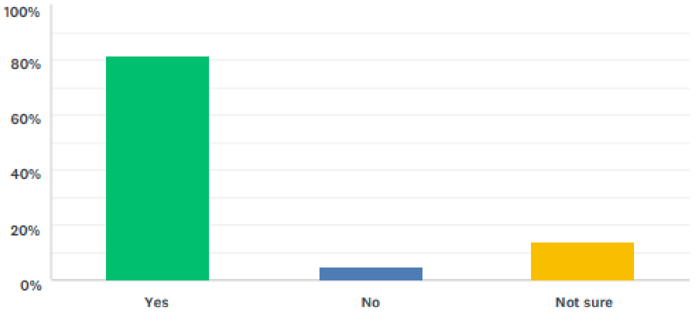
Others focused on some of the challenges with navigating the amount of information that could be presented to the professional and the need to be able to easily find important and relevant information, so the need to consider the amount and presentation of the information to the end users.

The responses that focused on specific information items or categorise covered 7 key themes:

- Social care – further work on care services/packages (including home care) and delivery, funding
- Patient entered health data – e.g. from wearables and apps
- Community recording
- Dental and optometry records
- Demographics – language preference, nominated pharmacy
- Medications – adherence, administration

2.9 Q9. ‘About me’ section for the person using services. This section is a record of the things that an individual feels it is important to communicate about their needs, strengths, values and preferences to others providing support and care. Should ‘About me' be prioritised as part of the core information for everyone involved in health and care?

Answered: 1,003 Skipped: 7



ANSWER CHOICES	RESPONSES	
Yes	81.56%	818
No	4.69%	47
Not sure	13.76%	138
TOTAL		1,003

- 81.56% of participants think ‘about me’ information should be prioritised as part of the core information record.
- No carers, pharmacists or midwifes responded saying that they didn’t think ‘about me’ information should be prioritised.
- Overall, less than 5% of respondents said they didn’t want ‘about me’ information to be prioritised. 12% of GPs and 7.32 % of doctors held this position, as did 5% of patients and people who use services.

238 people left comments

A number of themes emerged from the qualitative analysis:

Information being entered and kept up to date

- Concerns were expressed about who would enter the data (person using services or the professional), who would be responsible for it and how it would be kept up to date. The latter was identified by several respondents as a significant challenge.

Concerns about information overload

- Concern was raised that people might provide too much information for professionals to digest.

5. Other comments

Other notable comments included:

- Concern about disclosure of information not relating to the care being given
- Should be optional
- Especially important for those with complex needs or communication difficulties
- Provenance is important
- Needs to be structured to be useful
- Useful for unconscious patients / palliative / elderly to know advance directives etc
- Should include 'who is important to me'
- Helps carers convey to the professional who the person is
- Will need significant investment in training and incentives for it to be used.

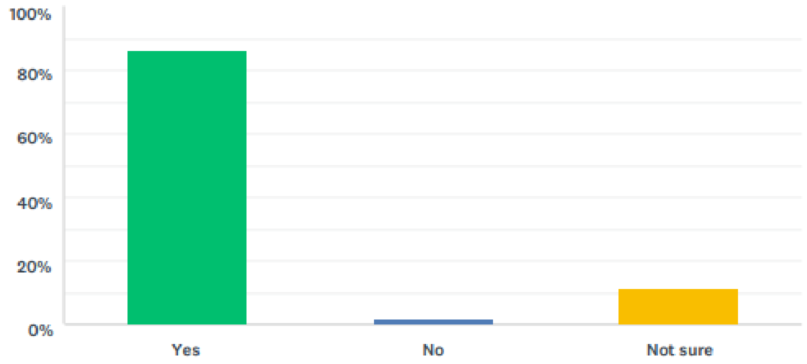
"It should become the norm, like a birth plan, for anyone with a health condition. But not compulsory. A patient passport model also works well" (OT in oncology + palliative care in an acute NHS hospital trust)

"Not necessarily a priority but would be useful to capture at some stage. Patient-centred approach is beneficial but could be challenging if patients or carers can directly upload their preferences in a shared record. How do we manage preferences such as 'I need home visits as I have no transport'? What happens if a patient uploads 'I don't want any tests or investigations as they are pointless' - how do we accept this/capacity to make decision/legal obligation to honour preferences. I think it will need more thoughts on this section." (GP)

"Definitely. I think we miss this information in services at the moment and it hinders the care we provide. This is the sort of information that care professionals can know which can make the care people receive exceptional rather than good. It is extremely important- especially for cultural or religious practices or preferences that a person might have. It can enable a discussion with the person about the care they receive and can enable teams to be more thoughtful and person-centred when delivering that care. I've experienced breakdowns in teams and relationships between patient and healthcare professionals because this sort of information has been missed or assumptions have been made and the person hasn't been involved in having a say about the care they receive. Even if that's as simple as "I don't like tea I like coffee," or "I don't feel comfortable with male staff providing my basic care needs- I would prefer female staff". (Clinical psychologist)

2.10 Q10. Alerts. This section is for any significant information meriting a specific and highly visible warning to any user (e.g. metallic implant, emergency keyholder information, potentially dangerous pet). Should alerts (e.g. metallic implant, dangerous dogs) be flagged as part of the core information set?

Answered: 1,003 Skipped: 7



ANSWER CHOICES	RESPONSES	
Yes	86.54%	868
No	1.79%	18
Not sure	11.67%	117
TOTAL		1,003

- 86.9 % of participants thought alerts should be flagged as part of the core information set.
- Fewer GPs (65%) think alerts should be flagged than any other group.
- No nurses, social care professionals or midwives disagree with sharing alerts

197 people left comments

A number of themes emerged from the qualitative analysis:

Information being reviewed and end date noted where appropriate

- Concerns were expressed about data being kept up to date, and an end date entered if an alert is no longer appropriate. "Dangerous dogs eventually die. Alerts live on."
- It was suggested that social care have good procedures for ensuring review and update.

Categorisation

- It was suggested that alerts be categorised so that they would only be shown if relevant to the professional, with many giving the example that a clinician would need to know about a medical implant but not a dangerous dog, whilst the reverse may be true for someone on a home visit.

Alert fatigue

- Concerns were expressed about information overload, with important alerts potentially being lost amongst more trivial information. In addition to categorisation, it was suggested that alerts should also be given a priority rating.
- In relation to this, it was suggested that data quality could be mixed.

Negative labelling

- Concerns were expressed about individuals being negatively labelled due to inaccurate or out-dated information.

Informing individuals

- The view was expressed that any alert raised should be notified to the individual concerned and that they should have access to the data held and have the ability to challenge it.

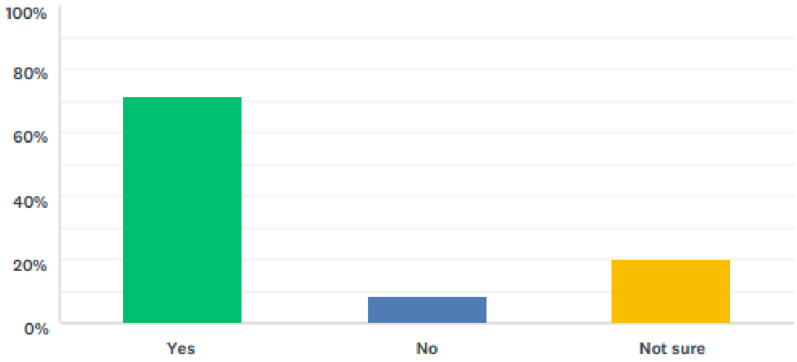
"Generally sharing would be helpful, however there are some possible operational issues which need considering. For example, the definition of 'alerts' may differ between health and social care systems, some of which may not be of value to share with other agencies. Typically, data quality on alerts can be mixed, and different agencies may have different review dates/procedures for managing alert information." ***(Social care professional, commissioning, local authority)***

"This section could easily become over used and important information be lost. It would be useful to split into categories e.g. information essential for medical treatment (metallic implant) vs info important for community care (dangerous dog), to allow people to filter what is relevant to them." ***(Clinical Neuropsychologist, acute hospital)***

"Unreported metal skull implants prevented urgent MRI scanning in a recent emergency" ***(Carer)***

2.11 Q11. Assessments. This section is for documenting assessment scales such as mental health assessment scales, New York Heart Failure, Activities of Daily Living (ADL). Should assessment summaries (which include written assessment outcomes for social care and mental health) be included in the core information set?

Answered: 1,004 Skipped: 6



ANSWER CHOICES	RESPONSES	
Yes	71.41%	717
No	8.37%	84
Not sure	20.22%	203
TOTAL		1,004

- Most groups expressed some uncertainty, with just under 30% of participants saying ‘not sure’ or ‘no’ to including assessment summaries in the core information set.
- Nurses and mental health professionals were most keen to include assessment summaries, more than 80% of both groups marked ‘yes’.

206 people left comments

A number of themes emerged from the qualitative analysis:

Information being entered and kept up to date

Particular emphasis upon:

- It should be an individual's decision as to whether assessment information is included or shared.
- The currency of the information held. Different views were expressed as to whether only the latest assessment should be held or whether history might inform decision making. What was universally agreed was that the information should be up to date and should perhaps include a future review date.
- Could an individual challenge information?

Concerns about Information overload

Concerns were expressed that there was a fairly high risk of information overload.
Suggestions ranged from:

- Flag that an assessment had been made, but with no detail
- Summary information only
- Summary, with link to detail

Security and confidentiality 'need to know'

- Many comments reflected (or referred to) those in question 4 responses. This included access on a 'need to know' basis, with data only being shared if relevant to the service being delivered.
- Two respondents commented on the high risk of information becoming available to third parties through coercion which might be detrimental to the individual, e.g. an abusive partner and suggested that this information should only be available to professionals.

Risk of negative labelling of individuals

- Several respondents commented upon the risk of individuals being negatively labelled due to out of date historic information and the need to ensure that information accurately reflects the current situation.

Avoidance of repetition and duplication

- Several comments identified a benefit being that this would reduce the number of times that individuals had to repeat information to different professionals, and for that information to be duplicated across services.

Other comments

Other notable comments included:

- There should be individual and professional-entered assessments
- A view was expressed that formulation (professional interpretation of results) was key; conversely the view was expressed that it was irrelevant as subjective
- The assessment should be linked to an encounter
- Avoid clinical jargon and make it easy for the individual to understand.

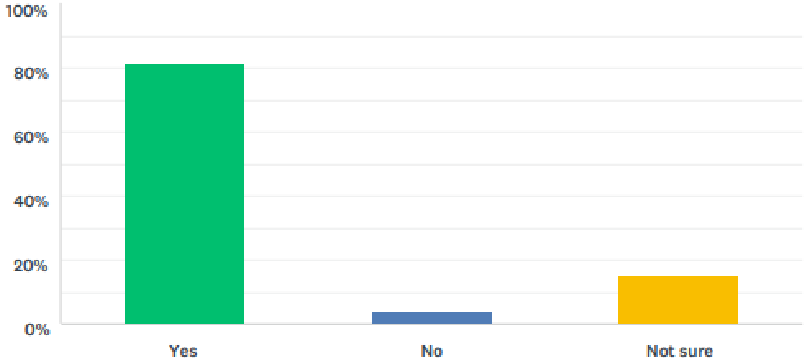
"As MIU practitioner/paramedic, having access to up-to-date ECG will help identify any new cardiac problems or confirm an existing problem normal for patient." (AHP, primary care)

"Mental health needs particular safeguards and should be considered separately." (Person who uses services and Carer)

"Assessments vary so widely, particularly the free text elements and lack of common assessment approach across health and social care. This will likely mean the key data for the front-line staff is in the free text, and the free text options will vary greatly. This makes commonality for sharing very difficult." (Business Analyst, social care, local authority)

2.12 Q12. Risks. Details of any risk a person poses to self, others or from others. This subsection is called risks. Does 'risks' describe this section well and is this what you would expect to see in it?

Answered: 995 Skipped: 15



ANSWER CHOICES	RESPONSES	
Yes	81.21%	808
No	3.52%	35
Not sure	15.28%	152
TOTAL		995

- No nurses, mental health and learning disability professionals or pharmacists responded negatively and only 2% of social care professionals disagreed.
- However, there was a lot of uncertainty across most groups. 15.28 % of all respondents said they were unsure. 24% of pharmacists and patients answered, ‘not sure’.
- Nurses responded most positively with 92.04% agreeing that ‘risks’ describes the section well and the contents are as expected. 87% of allied health professionals and 81.82% of carers also responded ‘yes’.

217 people left comments

A number of themes emerged from the qualitative analysis:

Information being entered and kept up to date

- Particular emphasis upon the fact that information was subjective and that it needed to be regularly updated; suggestion that a review date should be held.

Flag risks

- It was suggested that there could be a flag that risks existed (possibly colour-coded) so that professionals were immediately aware.

Security and confidentiality 'need to know'

- Many comments reflected (or referred to) those in question 4 responses. This included access on a 'need to know' basis, with data only being shared if relevant to the service being delivered.

Risk of negative labelling of individuals

- Several respondents commented upon the risk of individuals being negatively labelled due to out of date historic information and the need to ensure that information accurately reflects the current situation.

Context is key

- Whilst in part included in section two, the emphasis upon the importance of context and, in particular, date-stamping of information, makes this worth identifying as a theme in its own right.

Other comments

Other notable comments included:

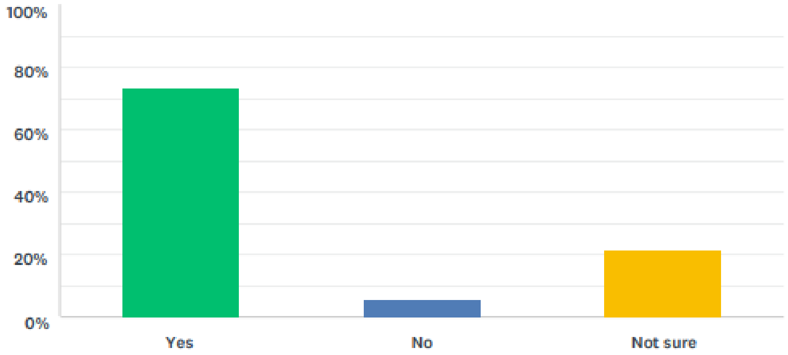
- How does an individual challenge information they perceive as incorrect?
- Link to risk mitigation
- Link to care / risk plans
- Suspected risk?

"Could these be prevented as safety awareness instead of risk? If I read that my relative was a risk to other patients I may be upset. However, if there was a safety awareness message as to why they were a risk to others it may be easier to take. Also, person reading the message could make a quick assessment of what safety equipment or care package needs to be in place to protect others or the patient themselves." ***(Neonatal Nurse, acute hospital)***

"Some elements of this are undoubtedly very useful, however, others appear quite vague. One question would be related to information that the individual is a potential risk to others - should the sharing of this data be exempt from sharing control by the individual? This information is vital for the likes of paramedics attending in an emergency situation and is the individual is at risk of being violent, then I personally would want this to be shared regardless of the individual's wishes." ***(eHealth Pharmacy Adviser, NHS National Services Scotland)***

2.13 Q13. Relevant past medical, surgical and mental health history. The record of the person’s significant medical, surgical and mental health history. Including relevant previous diagnoses, problems and issues, procedures, investigations, specific anaesthesia issues, etc (with obstetric history). Looking at the information below, is this all the information you need to share as part of the core information set about an individual's past pregnancy history?

Answered: 993 Skipped: 17



ANSWER CHOICES	RESPONSES	
Yes	72.91%	724
No	5.54%	55
Not sure	21.55%	214
TOTAL		993

- 21.55% were unsure whether the information we listed was all you need to share as part of the core information set about an individual’s past pregnancy history.
- No midwives said they weren’t sure, 83.33 % approved the information categories we identified for sharing regarding past pregnancy.
- 84.48 % of nurses responded ‘yes’ and no mental health professionals said ‘no’.

189 people left comments

A number of themes emerged from the qualitative analysis:

Currency of data

- Historic data should have an end date to indicate when it is no longer a current episode or diagnosis.

Why pregnancy specific?

- There was widespread questioning as to why past medical, surgical and mental health history was pregnancy-specific and not general.

Security and confidentiality 'need to know'

- Many comments reflected (or referred to) those in Question 4 responses. Overwhelming responses that information should be accessed on a 'need to know' basis, with data only being shared if relevant to the service being delivered.
- There was emphasis on the fact that some of this information is highly sensitive e.g. terminations, miscarriages, sexual health
- Two respondents commented on the high risk of information becoming available to third parties through coercion which might be detrimental to the individual, e.g. an abusive partner.
- A few respondents stressed that information should only be shared with persons' explicit consent.

Information overload

- The potential for information overload was stressed and suggestions ranged from simply flagging that there was information to be found elsewhere, or providing summary information, potentially ranked by importance.

Mental health history

- Several respondents stressed the need to include mental health history.

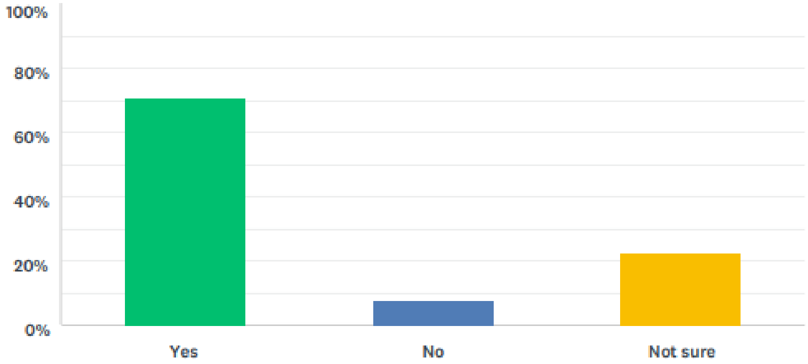
Other comments

Other notable comments included:

- The information will reduce in importance as a woman ages.

2.14 Q14. Pregnancy status. The pregnancy state relating to women. Should current pregnancy status be part of the core information set?

Answered: 984 Skipped: 26



ANSWER CHOICES	RESPONSES	
Yes	70.53%	694
No	7.32%	72
Not sure	22.15%	218
TOTAL		984

- There were varying views on whether pregnancy status should be recorded.
- All midwives who took part in the survey think current pregnancy status should be recorded in the core information standard, as do 95.24% of pharmacists.
- Social care is split with 51.85 of social care professionals agreeing that current pregnancy status should be included and 37% ‘unsure’.
- No carers said current pregnancy status definitely should not be recorded, however 39.39% were unsure about it.

162 people left comments

A number of themes emerged from the qualitative analysis:

Currency of Data

- The importance of this data being updated dynamically was stressed, particularly in the context of miscarriage.

Only if pregnant

- There was widespread response emphasising that this information should only be held if relevant. In particular, respondents did not want to record if women were not pregnant.
- It was observed that pregnancy status is relevant across many clinical settings and so was important to know.
- It was also identified that this would be age-appropriate, and that data could be archived, e.g. post menopause.

Security and confidentiality 'need to know'

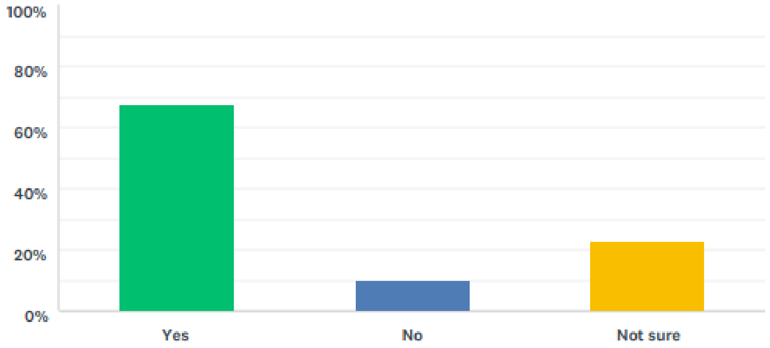
- Many comments reflected (or referred to) those in question 4 responses. Overwhelming responses that information should be accessed on a 'need to know' basis, with data only being shared if relevant to the service being delivered.
- Two respondents commented on the high risk of information becoming available to third parties through coercion which might be detrimental to the individual, e.g. an abusive partner.
- A few respondents stressed that information should only be shared with persons’ explicit consent

Importance for prescribing

- Several respondents commented upon the importance of this information for prescribing, including post birth.

2.15 Q15. Correspondence This is a section where any correspondence relating to the person can be stored. Should the core information set include correspondence such as outpatient letters or letters from patients?

Answered: 997 Skipped: 13



ANSWER CHOICES	RESPONSES	
Yes	67.60%	674
No	9.63%	96
Not sure	22.77%	227
TOTAL		997

- People using services and clinical participants had similar responses with approximately 60% of these groups indicating that they think correspondence should be included in the core information standard.
- Social care professionals were less sure, 56% agreed that correspondence should be shared.
- Vendor representatives, NHS administration and management and pharmacy were keener for correspondence to be shared with 70%-80% of people suggesting it should be included in the core information standard.

Only 42.42% of carers said 'yes', 48.48% said that they were not sure about including correspondence in the core information standard.

226 people left comments

A number of themes emerged from the qualitative analysis:

Is correspondence 'core'?

- Some respondents felt that correspondence was vital whilst others felt it was not 'core' information.
- Some expressed the view that all relevant information would be coded on the clinical system and so the source should not be required.
- A general consensus was that routine correspondence such as appointment letters should not be included.
- If correspondence is included, it would need to be indexed, structured and dated.

Security and confidentiality 'need to know'

- Many comments reflected (or referred to) those in question 4 responses. This included access on a 'need to know' basis, with data only being shared if relevant to the service being delivered.
- Many correspondents identified that individual consent should be required.

Information overload

- Many respondents commented on the particular risk of information overload if they needed to wade through correspondence in search of information. Some suggested summary information should be held.

Third party information

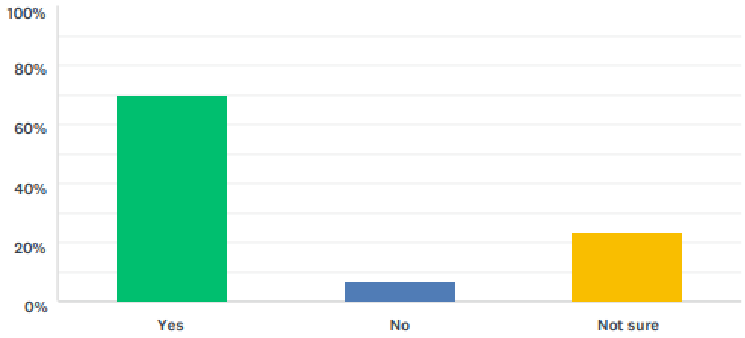
- Several respondents identified the risk that third-party information might be included in correspondence and this had legal implications.

"This is one of the most valuable features of a care record, especially when the development of the record is in its infancy. If you watch a doctor in out-patients with a fat set of paper records the first thing they do is turn to the last letter to the GP or the last discharge summary. These records summarise the care so far and are an excellent starting point for the current consultation." (Retired GP, primary care)

"Too wide a topic and an overwhelming amount of data could end up being shared that no clinician would have the time to wade through. The key data points should be covered in the other elements of the information set. I suggest seeing how long it would take to wade through just 20 documents to find out if there is any valuable data and consider the reality of this in clinical practice. Even with advanced document management structures and advanced searching capabilities based on character recognition this task just will take too long for most clinical scenarios." (Solutions management with focus on population health management and interoperability, third party supplier)

2.16 Q16. Safeguarding The following table of information is taken from the safeguarding and risks section of the core information standard. Should the core information set include details of historic (now closed) child protection plans? (A child protection plan acts to keep a child safe from abuse and neglect).

Answered: 998 Skipped: 12



ANSWER CHOICES	RESPONSES	
Yes	69.54%	694
No	7.11%	71
Not sure	23.35%	233
TOTAL		998

- All midwives think that the core information set should include details of historic child protection plans.
- Nurses and mental health professionals were keen to include historic plans with 85% and 83% responding ‘yes’.
- Only 50% of pharmacists and 58% of carers think historic plans should be included.

198 people left comments

A number of themes emerged from the qualitative analysis:

Differing views

- Historic information should not be held.
- Historic information should be held but for a limited time; between one to 10 years or on reaching adulthood (although some individuals may wish for the history to be held).
- A safeguarding flag could indicate that there had been a child protection plan (CPP) and the professional could find the information elsewhere (this was one of the most popular views).
- There could be a link to the historic CPP.
- An abridged version could be held.
- The historic CPP should remain as it may influence future care decisions.

Security and confidentiality 'need to know'

- Many comments reflected (or referred to) those in question 4 responses. This included access on a 'need to know' basis, with data only being shared if relevant to the service being delivered.
- Many correspondents identified that individual consent should be required.

Vulnerable adults

- Many respondents expressed the view that safeguarding should extend to vulnerable adults.

Overlap with risks / alerts

- Several respondents observed that there seemed to be an overlap with risks / alerts.

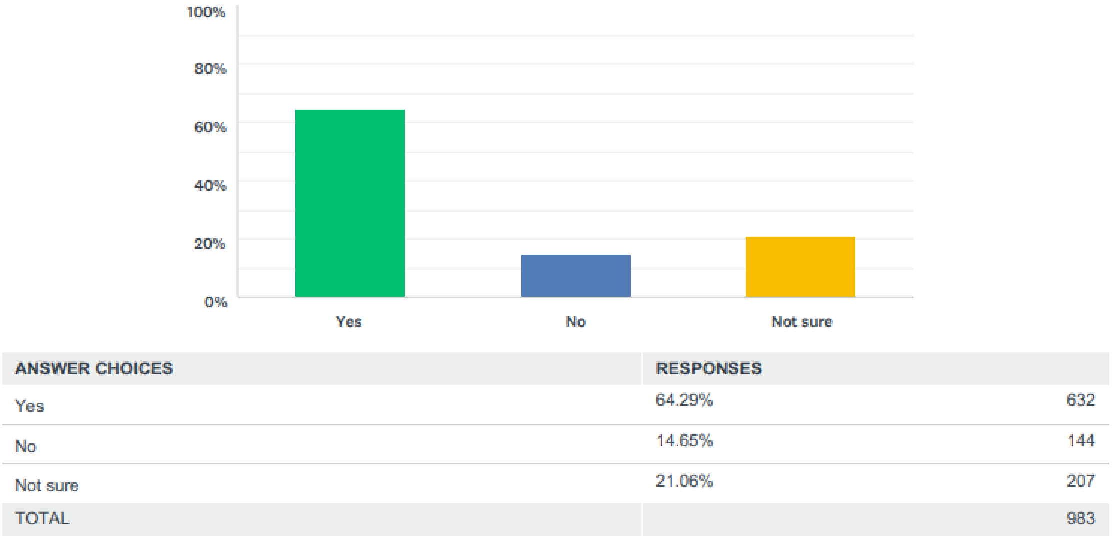
"This is already covered by the Child Protection Information Service. Every clinician with a valid need should have access to this service (not just in urgent care as it is available currently)" *(Person using services)*

"50% of safeguarding alerts to my (adults) team in social services are closed as not meeting s42 Care Act. 2/3 of those that do are minor, and the risk has been managed/ eliminated even before the report is made. I feel that only serious or ongoing concerns should be recorded" *(Social care professional, local authority)*

"Extensive training is required for good quality safeguarding recording and responding - is this issue and the risk of recording and responding (not responding) built into this transformation - the information cannot just be shared into already under skilled and overloaded health and care services" *(Specialist midwife for change and transformation, multi-sector partnership)*

2.17 Q17. Should disability be included as a separate section in the core information set? (Mobility, cognitive and accessibility disabilities are currently recorded in individual requirements).

Answered: 993   Skipped: 27



ANSWER CHOICES	RESPONSES	
Yes	64.29%	632
No	14.65%	144
Not sure	21.06%	207
TOTAL		983

- All midwives thought that disability should be included as a separate section of the core information set.
- Of all the other groups between 60 – 67 % said they think disability should be included as a separate section.
- Despite 64.29% of respondents answering 'Yes', the overwhelming view of respondents was that it was very important that the data was included but that it should be part of 'about me' and 'individual requirements' rather than a separate section.
- Several expressed the view that individuals don't want to be labelled by impairments.
- A small number of respondents felt that it should be separate so that it was quickly and easily accessed, rather than perhaps looking through textual information which might be time consuming.

154 people left comments

A theme emerged from the qualitative analysis:

Security and Confidentiality 'need to know'
- Many comments reflected (or referred to) those in Question 4 responses. This included access on a 'need to know' basis, with data only being shared if relevant to the service being delivered.

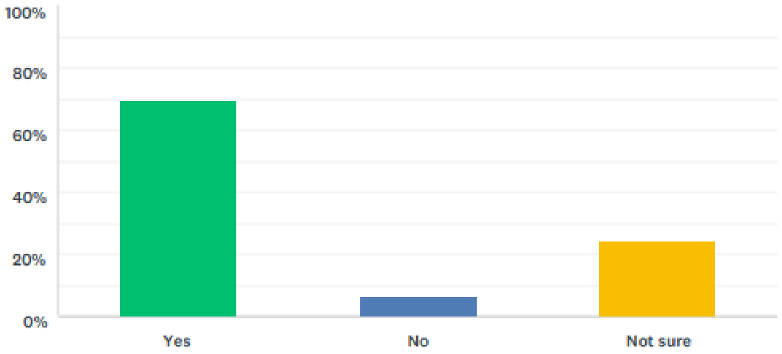
"This information often gets overlooked or swamped by a medical model of care. It is important in its own right." ***(OT in Oncology + palliative Care in an Acute NHS Hospital Trust)***

"Support requirements should definitely be shared (the NHS England Learning Disability and Autism Forum told us this). The disability diagnosis is less important- some people want to share this, some people don't. So, things like adjustments to information, access, environment, treatment etc" ***(Public engagement manager for learning disability and autism)***

"As a disabled person with multiple health conditions managing their own care, I can't access this at the moment and it would be so helpful to me if I could." ***(Patient)***

2.18 Q18. End of life This is the 'End of life' section in the draft core information standard. Please read through the contents and answer the question below. Is this all the information needed for end of life care as part of the core information set?

Answered: 994 Skipped: 16



ANSWER CHOICES	RESPONSES	
Yes	69.11%	687
No	6.74%	67
Not sure	24.14%	240
TOTAL		994

- 78% of clinical respondents think that we have included all the end of life information needed for the core information set.
- 68% of allied health and social professionals think the information we have included is correct.
- 59% of carers and 62% of patients are happy that we have included all the information needed for end of life care, as part of the core information set.

212 people left comments

A number of themes emerged from the qualitative analysis:

Person-centred
• The observation was made that this should be more person-centred. There is a section for professional comment but not for individual or family comment. There is also a need to know whether the family has been involved in or is aware of preferences.
Timeliness of data
• There is a need to ensure that this data is the most up to date and is accurate; DNR decisions can change and erroneous data could result in a death.
Estimated prognosis
• Several respondents felt that this should not be included due to the fact that it is often inaccurate.
Hospices and organisations that support end of life care
• There will be a requirement to share this data with hospices and organisations that support end of life care.

"You may also want to consider wishes for organ donation/medical research" (Business and performance lead, mental health/ learning disability hospital)

"Should it reference a RESPECT form if completed or other recognised end of life plans." (Person using services)

"This is a section where the person really could contribute and make their wishes known end of life wishes, e.g. food/drinks places and people music and light/comfort Living will could be attached. Continuing healthcare status DST attached Donor status also could be included, e.g. organs and preferences crematorium /burial funeral plans if no next of kin." (OT, community care)

2.19 Q19. Do you have any comments you would like to add before submitting the survey?

Answered: 253 Skipped: 757

A number of themes emerged from the qualitative analysis:

Information governance
There is extensive concern about information governance in terms of: • What exactly are the rules? • Will access be restricted to role-based 'need to know'? • How secure and confidential will data be? There is a real concern that data will be hacked or will be sold to third party organisations for profit which will be to the detriment of the individual • What control will individuals have over giving consent for access in a flexible way; will they be able to give consent for some access but opt out for others? • Will individuals be able to correct or comment on information? • Will individuals have access to and control of all their data 'nothing about me without me'? • What, if any, plans are there to anonymise data and use for public health research and analysis? • A particular concern is that if individuals are not confident that data is secure they may withhold private and sensitive information which may increase the safety risk.
Information is up to date
• The need for data to be kept up to date was consistently raised across many sections, in particular risks and alerts, and the risk of individuals being negatively labelled. • This was raised as a particular risk for DNR information. An individual's preferences may change as their situation changes and so having the most up to date information is vital. It is also essential that the information is verified as correct. • The question was raised as to who would have responsibility for ensuring information was up to date and accurate, particularly where data might be extracted from more than one source system.
Information overload
• If user interface is not well-designed, there is a risk of information overload and not getting to the required information effectively and efficiently; this will require role-based access design.
Ambitious scope
• Some concerns were raised that the scope of the standard is too ambitious and is more encompassing than 'core'; this requires widespread communication of the core information narrative.
Person held data
• Although not a 'theme' as such, a couple of respondents raised the suggestion that the patient should have a card with their data stored upon it which they should take with them to interactions.

"The standards overall don't address concerns about the scope of access across a wide range of health and social care agencies. What happens when people don't wish for more sensitive information (e.g. HIV status, trauma history, domestic violence, details of therapy sessions) to be widely and readily accessible to all health/ social care professionals involved in their care?" *(Consultant clinical psychologist, community care)*

"The accuracy and pertinence of this data could become a burden on healthcare professionals. There is no guarantee that any records will be maintained and utilised correctly. Not having access to accurate and timely healthcare records can hinder treatment and increase harm. However the task to standardise this across so many systems and individuals is gargantuan." *(Pharmacist, primary care)*

"I work in the Out of Hours setting and often meet patients and their families for the first time before having to make complex decisions about their on-going care. Having access to all of the above, in an accessible format, would improve their care considerably." (GP, urgent care services)

3 Conclusion

The findings detailed in this report have been synthesized and summarised in the core information standard final report, together with recommendations. Suggestions for additional requirements for the core information standard have been considered for inclusion in this release or future releases of the standard.