PRSB Professional Record Standards Body

Better records for better care

Digital Maternity Record Standard Release 2 Survey Report

October 2024

Document Management

Revision History

Version	Date	Summary of Changes
0.1	04/06/2024	Initial version
1.0	03/10/2024	Updated following review

Reviewers

Reviewer name	Title / Responsibility	Date	Version
Adrianna Szczypkowska	Communications Officer, PRSB	20/09/2024	0.1

Approved by

Name	Title / Responsibility	Date	Version
Project Board			
Assurance Committee			

Glossary of Terms

Term / Abbreviation	What it stands for
ADHD	Attention Deficit Hyperactivity Disorder
ANC	Antenatal Care
BMI	Body Mass Index
BRAIN	Benefits, Risks, Alternatives, Intuition, Nothing
CNIO	Chief Nursing Informatics Officer
CNST	Clinical Negligence Scheme for Trusts
CPTSD	Complex Post-Traumatic Stress Disorder
DMRS	Digital Maternity Record Standard
E.g.	Exempli Gratia (For Example)
FASD	Fetal Alcohol Spectrum Disorders
FHIR	Fast Healthcare Interoperability Resources
GP	General Practitioner
HCP	Healthcare Professional
ICB	Integrated Care Board
IM&T	Information Management and Technology
IT	Information Technology

IVF	In Vitro Fertilisation
LGBTQIA+	Lesbian, Gay, Bisexual, Transgender, Queer/Questioning, Intersex, Asexual +
LMNS	Local Maternity and Neonatal Systems
MARAC	Multi-Agency Risk Assessment Conference
MBRRACE-UK	Mothers and Babies: Reducing Risk through Audits and Confidential Enquiries across the UK
MCoC	Midwifery Continuity of Carer
MDT	Multidisciplinary Team
MIS	Maternity Incentive Scheme
MSDS	Maternity Services Data Set
N/A	Not Applicable
NHS	National Health Service
NHSE	National Health Service England
NICE	National Institute for Health and Care Excellence
OASI	Obstetric Anal Sphincter Injury
PBR	Payment by Results
PCSP	Personalised Care and Support Plan
PRSB	Professional Record Standards Body
PTSD	Post-Traumatic Stress Disorder
QA	Quality Assurance
QI	Quality Improvement
QS	Quality Standard
UK	The United Kingdom
UX	User Experience

Gender Inclusivity

While most people using maternity and perinatal services are women, the Care Quality Commission (CQC) Maternity Survey 2023 (2024) found that 0.77% of respondents stated that their gender was not the same as their sex registered at birth. Intersex, transgender, and non-binary people experiencing pregnancy and birth can experience health inequalities including poorer access and a lack of information and support in relation to their specific clinical and care needs within maternity services. The content in this document also applies to these individuals.

Contents

1 Introduction

This is an appendix to the final report for the Digital Maternity Record Standard Release (DMRS) 2 project.

One online survey was distributed to service users, maternity care providers, and maternity system suppliers to gather quantitative and qualitative data to inform the further development of the draft information standard. The full list of survey questions is included in Appendices A-D.

2 Methodology

2.1 Survey Overview

Following the webinars and workshops, an online survey was conducted via SurveyMonkey. The questionnaire intended to gather qualitative and quantitative data to inform the further development of the standard. The Professional Record Standards Body (PRSB) Communications, Engagement and Strategy team distributed the survey through social media channels, through email, and through existing lists of people connected to maternity and the maternity project, and minority groups who may be underrepresented.

The survey consisted of 4 pathways depending on the type of respondent:

1. **Service Users** (See Appendix A for this pathway's questions.)

2. **Easy Read** (See Appendix B for this pathway's questions.)

3. **Maternity Professionals / Care Providers** (See Appendix C for this pathway's questions.)

4. **Maternity System Suppliers** (See Appendix D for this pathways questions.)

The survey was open from Monday 12th February 2024 – Friday 1st March 2024.

2.2 Scope

The survey was:

- For testing the draft content of the DMRS with the people who will use it by gathering evidence to support / oppose the inclusion of existing sections and elements and to identify any new areas to incorporate as required.
- To better understand issues that may affect the implementation of the standards in the real world and the potential impact on people who will use them.
- A short and pragmatic exercise to engage stakeholders.

Caution should be applied when drawing inferences that may not be generalisable to the wider population of the United Kingdom (UK) and four nations. The information may be representative of the views of some or even many maternity professionals or service users, but it was not the intention of this exercise to draw conclusions beyond those relevant to guiding us in the development of the standard's content.

3   Survey Analysis

3.1 Service Users

3.1.1 Service Users Analysis – Overview

Two hundred and thirty-nine participants service users completed the survey. All available information and responses were analysed, although some questions were unanswered by respondents.

The demographic questions revealed a wide range of representation across postcode deprivation scores, age, and sexual orientation. Some attributes were less diverse. Most respondents identified English as their primary language, and most female respondents stated they had the same gender as their birth, with only one respondent identifying as non-binary and two people preferring not to say if their gender matched their sex assigned at birth. Ninety five percent of participants identified themselves as belonging to a white ethnic group, (excluding those in mixed or multiple ethnic groups that include a white category). There was minimal representation from individuals belonging to other religions outside of Christianity or no religion.

There were several respondents who identified themselves at having a long-term physical or mental health condition, disability, or were neurodiverse.

Occupation was not requested per se, but respondents were asked about caring responsibilities or whether they served in the armed forces of which several were carers (22), and several served in the armed forces or had a partner who served in the armed forces (6).

Respondents were asked whether they thought their maternity care professional had enough information to provide personalised care. Only 6% of respondents reported that health care providers had 'very little or no information.' However, a much higher percentage of respondents reported that healthcare providers did not know important information about them, their pregnancy, or their child which led to them repeating information multiple times to multiple healthcare providers including distressing or traumatic information.

Several respondents expressed challenges in decision-making arising from inadequate information from care providers. The lack of information reduced respondents' ability to make well-informed decisions, led to a perceived lack of choice about their care, or a sense that their choices were not respected, and occasionally respondents felt under pressure to change their decisions.

Respondents indicated that the following information was the most important for health professionals to know when caring for them:
- Physical health history (60%)
- Mental health history (58%)
- Previous pregnancy experience, including complications (70%)
- Previous pregnancy loss (50%)
- Safeguarding information (44%)

Information about them, their family and household, cultural background and identity were the only indicated as 'somewhat important' (42%). Respondents commonly identified other pertinent information, such as birth plans, treatment preferences, neurodiversity, and the use of in vitro fertilisation (IVF), as important for their maternity team to be aware of.

Many respondents expressed a desire to have the option to give consent to sharing specific information, (particularly related to their mental health), with all healthcare providers involved in their care.

Many respondents reported having consistent support from the same community midwife for most or all their maternity journey. In cases where the respondent did not have Midwifery Continuity of Carer (MCoC), the respondent indicated that the midwife lacked comprehensive knowledge about them.

Forty-eight per cent indicated they could talk to their midwife about everything they wanted to, plan, and make decisions about their pregnancy, whilst 43% indicated that they did not talk to their midwife as much as they would have liked.

Most respondents had access to their maternity records in paper or digital formats (88%), with 40% having access via paper maternity records. However, most respondents expressed a preference for mixed maternity notes, i.e. in both paper and digital formats (43%). Respondents agreed that their records were:
- Reflective of their needs and wishes (36%)
- Up to date (47%)
- Easy to understand (38%)
- Complete (32%)

33% of respondents recorded that their notes were useful in helping them plan their care with 30%) giving a neutral response and 27% stating their records were not helpful (101 skipped the question). Respondents also indicated that their notes could have been improved by completing missing information, including information about themselves being updated, and being in greater detail.

Most respondents did not get to keep their maternity records after their pregnancy ended (73%), but most respondents would have liked to do so (86%) to ensure it was available for future pregnancies and for their own information.

For those who had used a maternity app, the most popular reasons for use were to view appointments, understand their care, and review test results. Respondents indicated that they would want to use the maternity records app for the following:
- Add and update information about them or their health (65%)
- Communicate with their midwife or doctor (80%)
- Understand their care, treatment, and test results (81%)
- View appointments (74%)
- Book and change appointments (84%)

The service user survey revealed disparities in the amount of information healthcare providers recorded or had access to about the person using their services and this could cause upset and errors in providing effective care. There is a clear desire for people to have greater involvement in decision-making, with an emphasis on having choices respected and there are clear benefits in having continuity of care. There is also a clear desire for people to have diverse means of accessing their maternity information, even beyond the pregnancy period. It is important to interpret these findings with caution due to underrepresentation of specific demographic groups.

3.1.2 Service Users Analysis – Question Responses

Did the maternity team, and others who cared for you during and after your pregnancy, have all the information they needed to provide care that was right for you?

ANSWER GROUP	ANSWER	RESPONSES	PROVIDED MORE INFORMATION
1	Everyone had enough information	52	3
2	Some knew everything, others had little or no information	63	21
3	They knew about most things but not always	52	17
4	They had some information but there were gaps	56	38
5	They had very little or no information	15	12
6	Don't remember	1	0
	Please tell us more about this	91	
	Total Respondents	**239**	

The additional information provided was analysed for themes. The table below shows each theme, as well as the number of respondents who mentioned the theme in each answer group.

THEME	ANSWER GROUP					
	1	2	3	4	5	TOTAL
HCP* did not know important information me/my pregnancy (even though it should be in my notes), either due to not reading notes or missing information.	0	11	6	18	6	40
HCPs did not seem to share information with each other.	0	5	4	10	4	23
HCP perceived to have gaps in clinical knowledge.	0	5	2	8	2	17
I had to repeat information to HCPs, including upsetting/traumatic information.	0	4	2	7	2	15
HCPs did not share important information with me (e.g., about risks, outcomes etc.), meaning I did not always make informed choices.	0	2	3	6	1	12
My wishes/right to choose were not respected at face value and I had to repeatedly defend my preferences OR I faced a negative reaction in response to my wishes/preferences/choices.	0	1	2	4	4	11
Respondent had positive sentiments about at least one HCP throughout their maternity journey.	1	7	2	1	0	11
Knowledge/option(s) were presented to me without element of patient choice.	0	1	1	3	3	8
HCP dismissed information / my concerns as unimportant.	0	2	1	2	2	7
Had information but did not use it to provide care that was right for me/my baby.	0	3	0	0	3	6
Incorrect information was on my healthcare record OR HCP had incorrect/assumed information about me/my baby.	0	1	2	1	2	6
Information not carried over from previous pregnancies.	0	1	0	2	2	5

Issues with information sharing when accessing services outside of local area / between different trusts.	0	0	1	2	1	4
Language, attitudes, actions towards, and knowledge about LGBTQIA+ relationships were not appropriate.	0	2	1	1	0	4
HCPs would disagree about what the best care for me was / some HCP dismissed information as unimportant whilst others believed it was important for my care.	0	0	1	2	0	3
Lack of trust / trauma from experiences.	0	0	0	2	1	3
Experienced delays in upload of information to maternity system.	0	1	0	1	0	2
HCP had good clinical knowledge.	0	1	1	0	0	2
HCP had the information they needed about me throughout my care.	2	0	0	0	0	2
HCP were rude/abusive about/to me, either in my notes or to my face.	0	0	0	0	2	2
I concealed/withheld information due to safety concerns (e.g., abuse) or lack of trust.	0	0	1	1	0	2
Loss of pregnancy due to inadequate care or lack of information sharing.	0	0	0	1	1	2
HCP would not/could not access my maternity app.	0	1	0	0	0	1
HCP would/could access my maternity app.	1	0	0	0	0	1
I had information I wanted to share but did not know who to share it with.	0	0	0	1	0	1
I revealed sensitive information to an HCP because I felt comfortable doing so.	0	0	1	0	0	1
I was not contacted by maternity team after ectopic pregnancy, only by my GP.	0	0	0	1	0	1
Information not being shared between NHS and private care.	0	0	0	1	0	1
Records did not facilitate recording multiple foetuses.	0	0	0	0	1	1
Records did not facilitate recording reciprocal IVF situations.	0	0	1	0	0	1
There was a lack of knowledge around my accessibility needs.	0	0	0	1	0	1

*HCP – Healthcare Professional

If they didn't, what impact did this have on you and your pregnancy experience?

ANSWER CHOICES	RESPONSES
I had to repeat information multiple times to different people	140 (59%)
I felt I had to be responsible for making sure information was known and shared	123 (51%)
I felt worried that the people looking after me wouldn't know my needs and wishes	92 (38%)
I had to do my own research into things I was told in appointments and what they meant for my options and risks in my pregnancy	104 (44%)

Teams didn't always know why I was being seen or what my appointment was for	58 (24%)
I had to relive traumatic experiences from previous pregnancies several times	43 (18%)
Not applicable	52 (22%)
Other (please share your experience)	11 (5%)
Total Respondents	**239**

Other responses include:

- Worsened mental health and subsequent lack of trust in the system.
- Lost pregnancies and potential loss of pregnancies.
- Denied prescribed drugs that were prescribed by the same hospital due to no records taken.
- Was hurt at one appointment and midwife lack of knowledge affected birth in undisclosed way.
- Minimal impact.
- Life-altering choices were precluded from them.
- Lack of knowledge around options for labour (technique and pain relief), meaning gave birth in position that was not the most comfortable and had little understanding of what was going to happen or what could be done to support self.
- Had to correct misinformation following birth.
- Fear of being given an allergen and not being able to self-advocate.
- Lack of knowledge/guidance around multiple births.

Did you have the same community midwife during your pregnancy?

ANSWER CHOICES	RESPONSES
Everyone had enough information	52 (22%)
Some knew everything, others had little or no information	63 (26%)
They knew about most things but not always	52 (22%)
They had some information but there were gaps	56 (23%)
They had very little or no information	15 (6%)
Don't remember	1 (<1%)
Total Respondents	**239**

If you didn't, did the midwife make sure they knew enough about you from your notes, to provide the care you needed?

THEME FROM RESPONSE	RESPONSES MENTIONING THEME
No.	32
Yes.	28
Had little contact with their MCoC across pregnancy.	5
Confirmation that they had MCoC.	4
It was inconsistent whether they knew enough.	4
Was told/inferred/saw that they did not read their notes before appointments.	4
Changed midwives due to changing trusts.	2
Confirmation that they did not have MCoC, but no reference to information sharing.	2

The midwives would read their notes at the appointment.	2
Changed MCoC by choice for convenience with appointment times.	1
Incorrect notes in general.	1
Issues with doctors/consultants not having information rather than midwives.	1
N/A as they are out of area for MCoC.	1
Only had MCoC due to paying privately.	1
Only trusted their MCoC for care.	1
Poor information sharing when changing midwives due to changing trusts.	1
Poor relationship with MCoC made experience worse.	1
The midwives tried to have enough information.	1

How important is it to you that the people caring for you during your pregnancy know about the following?

ANSWER CHOICES	NOT IMPORTANT	SOMEWHAT IMPORTANT	VERY IMPORTANT	DON'T KNOW	NOT APPLICABLE	TOTAL
Physical health history	12 (5%)	61 (27%)	134 (60%)	1 (<1%)	16 (7%)	**224**
Mental health history	15 (7%)	36 (16%)	130 (58%)	1 (<1%)	42 (19%)	**224**
Previous pregnancy experience, including complications	4 (2%)	32 (14%)	157 (70%)	1 (<1%)	29 (13%)	**223**
Previous pregnancy loss	5 (2%)	28 (13%)	113 (50%)	3 (1%)	75 (33%)	**224**
Information about you as a person; your family and household, cultural background and identity	39 (17%)	94 (42%)	75 (34%)	4 (2%)	11 (5%)	**223**
Safeguarding information	12 (5%)	35 (16%)	99 (44%)	1 (<1%)	77 (34%)	**224**

Are there other types of information that are important for your maternity team to know about you?

THEME FROM RESPONSE	RESPONSES MENTIONING THEME
Birth plan / preferences / general maternity preferences.	21
IVF pregnancy.	4
Neurodiversity.	4
A desire for preferences to be respected at face value, without having to reconfirm.	3
LGBT+ inclusivity (around language, paperwork allowing for genders other than woman etc.)	3
Relationship status.	3
Access requirements/accommodations needs (e.g., interpreter needed).	2

Allergies and intolerances.	2
Anxiety.	2
Language around sperm donors (not referring to them as the father).	2
Mental health (including postnatal mental health from previous pregnancies).	2
Past experiences with NHS.	2
Previous pregnancy loss and implications.	2
Previous pregnancy/birth experiences.	2
Previous trauma.	2
A desire for HCP to have more up-to-date knowledge.	1
Cross-trust appointments.	1
Deafness.	1
Family history/genetic disorders.	1
Job/occupation.	1
Means of getting pregnant (e.g., IVF).	1
Multiple pregnancy.	1
Name pronunciation.	1
Past social issues (e.g., housing instability).	1
Previous medical history if new to hospital/area.	1
Reason for choice of maternity hospital.	1
Reason for IVF.	1
Religious requirements.	1
Thoughts and feelings about pregnancy.	1
Topics that they wish to not discuss at each appointment.	1
Who to contact about physical health history.	1

Did you talk about the things listed above with a midwife to discuss, plan and make decisions about your pregnancy?

ANSWER CHOICES	RESPONSES
Yes, we talked about everything I wanted to	109 (48%)
A little, but not as much as I would have liked	98 (43%)
No, not at all	16 (7%)
Don't remember	4 (2%)
Total Respondents	**227**

Is there any information you would want to agree first, before it was shared with the people caring for you?

THEME FROM RESPONSE	RESPONSES MENTIONING THEME
Yes, there is information they would want to agree first (this may be general yes responses, or include specific elements mentioned in this table).	22
No information they would want to agree first.	19

Yes – mental health information / history.	10
Did not understand the question.	5
Mentions they wished their decisions / wishes were respected.	4
Yes – all information.	3
Expressed that they wanted to share their wishes with someone but were unable.	2
All information should be shareable with consent.	1
Expressed that they did not want to be asked about previous losses.	1
Mentioned that important decisions about their care were put off until 36 weeks.	1
Mentioned they wanted the biological mother to be able to attend appointments without being questioned on why she was there.	1
Yes – birth plan.	1
Yes – domestic violence.	1
Yes – information told in confidence to the midwife.	1
Yes – previous pregnancy loss.	1
Yes – pronouns.	1
Yes – safeguarding.	1
Yes – weight.	1

Were you able to see your maternity notes?

ANSWER CHOICES	RESPONSES
Yes, I had paper maternity notes	110 (50%)
Yes, I used an app to view a digital version	67 (30%)
Yes, I had both paper notes and an app	18 (8%)
No, I had no access to my maternity notes	26 (12%)
Don't remember	0 (0%)
Total Respondents	**221**

How would you prefer to have your maternity notes?

ANSWER CHOICES	RESPONSES
In paper format	46 (21%)
Using an app or online	76 (34%)
Both paper and using an app	94 (43%)
Neither, I don't want to see my notes	1 (<1%)
No preference	4 (2%)
Total Respondents	**221**

The information I could see in my maternity notes was...

ANSWER CHOICES	STRONGLY DISAGREE	DISAGREE	NEITHER AGREE OR DISAGREE	AGREE	STRONGLY AGREE	TOTAL
Reflective of my needs and wishes	20 (9%)	40 (19%)	59 (28%)	76 (36%)	18 (8%)	213

Up to date	19 (9%)	35 (16%)	32 (15%)	101 (47%)	28 (13%)	**215**
Easy to understand	19 (9%)	52 (24%)	50 (23%)	82 (38%)	12 (6%)	**215**
Useful to help me plan my care	26 (12%)	51 (24%)	65 (30%)	57 (27%)	15 (7%)	**214**
Complete	30 (14%)	57 (27%)	42 (20%)	69 (32%)	16 (7%)	**214**

Would anything have made your experience better?

THEME FROM RESPONSE	RESPONSES MENTIONING THEME
Information that was missing from my record should be filled in.	14
Information should be updated to the app / record.	10
More detailed notes.	10
Access to test results.	8
Inaccurate information was recorded / should be rectified.	8
Easier navigation / better UX for app.	7
Notes updated in a timelier manner.	7
There was lack of access to the information that they wanted to see.	7
A focus on patient wishes / preferences.	5
Medical jargon / abbreviations either explained or not used.	5
Notes being clearer.	5
Reported having no access to any of their notes throughout.	5
Appointment summaries / details of what happened at each appointment.	4
Want to see all of their notes.	4
Desire to keep notes after birth.	3
Explanation for what was written and why.	3
Information about appointments.	3
Scan information/reports.	3
Ability to add to own notes.	2
Being able to see information upon request without having to chase people down for it.	2
For notes to be accessible online.	2
HCP to read their notes before appointments.	2
Incomplete notes made it harder to make informed decisions.	2
Information about their HCP (e.g., name, contact info).	2
Labour information.	2
Midwives were writing notes that the respondent perceived to be reflecting poorly on them due to their preferences.	2

More consideration about terminology / language used (e.g., parent>father; language around weight.)	2
Notes only accessible on computer which they could not access.	2
Use of different apps by different midwives / trusts causing issues with interoperability.	2
A willingness to amend incorrect notes.	1
Access to hospital policies.	1
Access to online notes rather than paper, for personal and shared access with midwife.	1
Access to personalised growth chart.	1
Accurate and full information recorded at time of appointment.	1
Appropriate information sharing between teams.	1
Assumptions not made and put into record (one respondent mentioned a midwife had guessed she was white British from a telephone appointment, which made her miss screening for sickle cell and thalassemia.)	1
Baby's engagement.	1
Baby's position.	1
Bump progress.	1
Clear sight of personal information for the person themselves.	1
Conversations around what was being recorded and mutual agreement on it.	1
Doctors' notes as well as midwives.	1
Focus on wellbeing.	1
Handwriting should be legible on written notes.	1
HCP to be up to date with NICE guidance.	1
Induction information.	1
Information about next steps.	1
Information about sperm donor.	1
Knowing more about aftercare.	1
Medication information.	1
Not having to change GP to be in the right county when on county lines.	1
Noted that they had declined vaginal examination.	1
Old information was recorded on record that did not feel relevant (i.e., inconsistent marijuana use over 10 years ago being marked as history of substance misuse, or seeing someone for anxiety as a teenager 15 years ago.)	1
One set of notes throughout the pregnancy.	1
Poor notes made the experience more stressful.	1
Training on how to use app.	1

At the end of your pregnancy, were you able to keep a copy of your maternity notes?

ANSWER CHOICES	RESPONSES
Yes	37 (17%)
No	161 (73%)
Don't remember	23 (11%)
Total Respondents	**221**

Did you want to keep a copy of your notes to support your postnatal care, your baby's care or future pregnancies?

ANSWER CHOICES	RESPONSES
Yes	190 (86%)
No	15 (7%)
I don't know or have no preference	16 (7%)
Total Respondents	**221**

What did you use your maternity notes app for?

ANSWER CHOICES	RESPONSES
Adding and updating information about me or my health	23 (28%)
Speaking to my midwife or doctor	10 (12%)
Sharing information with my family and friends	7 (9%)
Understanding my care, treatment and test results	54 (67%)
Viewing appointments	61 (75%)
Booking and changing appointments	9 (11%)
Don't remember	1 (1%)
Other (please specify)	12 (15%)
Total Respondents	**81**

Other responses included the following themes:

THEME FROM RESPONSE	RESPONSES MENTIONING THEME
Unable to see most information, but wanted to review information that was accessible.	4
Nothing / did not use it	3
Delivery/birth notes.	2
Add information about birth plan.	1
Checking that what was written reflected what was discussed in appointments.	1
Consultant notes.	1
Reviewing notes after birth.	1

Postcode

A range of postcodes were provided, and deprivation rankings were sought from each postcode.

DEPRIVATION RANKING	FREQUENCY
1	11
2	17
3	18
4	17
5	19
6	16
7	20
8	18
9	21
10	20
Not available*	24

*Some rankings were not available due to participants providing incomplete/incorrect postcodes.

Age

AGE	FREQUENCY
0-17	1*
18-24	9
25-34	124
35-44	70
45-54	1
55-64	0
65+	0

*This respondent noted their age as '1'.

Main Language

RESPONSE	FREQUENCY
English	192
British	2
English (but native German)	1
English/British Sign Language	1
English/Spanish	1
Greek	1
Italian	1
Polish	1
Portuguese/English	1
Swedish/English	1
UK	1

Gender

RESPONSE	FREQUENCY
Female	205
Non-binary	1
Does not believe in gender (but stated sex as female)	1
Male	0

Is your gender identity the same as the sex you were assigned at birth?

RESPONSE	FREQUENCY
Yes	202
No	1
Not sure	0
Prefer not to say	2

Sexual Orientation

RESPONSE	FREQUENCY
Straight/heterosexual	151
Bisexual	37
Gay or lesbian	13
Pansexual	3

Religion

RESPONSE	FREQUENCY
No religion	121
Christian	66
Pagan	5
Spiritual/spiritualist	4
Muslim	3
Catholic	1
Christian pagan	1
Jewish	1
Sikh	1
Buddhist	0
Hindu	0

Ethnic Group

RESPONSE	FREQUENCY
Asian, Asian British - Indian	2
Asian, Asian British - Pakistani	0
Asian, Asian British - Bangladeshi	0
Asian, Asian British - Chinese	0
Asian, Asian British - Any other Asian background (please specify below)	0
Black, Black British, Caribbean or African - Caribbean	1
Black, Black British, Caribbean or African - African	2
Black, Black British, Caribbean or African - Any other Black background (please specify below)	0
Mixed or multiple ethnic groups - White and Black Caribbean	1
Mixed or multiple ethnic groups - White and Black African	1
Mixed or multiple ethnic groups - White and Asian	2
Mixed or multiple ethnic groups - Any other mixed background (please specify below)	0

Other ethnic group - Arab	1
Other ethnic group (please specify below)	0
White - English, Welsh, Scottish, Northern Irish or British	175
White - Irish	3
White - Gypsy or Irish Traveller	1
White – Roma	0
White – Any other White background (see below)	17

The 17 responses to 'White – Any other White background' specify their background below.

RESPONSE	FREQUENCY
Did not specify	7
European	2
Eastern European	1
Greek	1
Latin American	1
New Zealand	1
Northern European	1
Swedish	1
White Asian (Indian)	1
White Southern European	1

Describe your household

THEME FROM RESPONSE	RESPONSES MENTIONING THEME
Two adults and at least one child in household.	165
Single parent.	17
Blended family / stepfamily.	7
In a same-sex relationship.	6
Multigenerational / extended family living in household.	5
Two adults and no children and does not state that they are currently pregnant.	4
Two adults and no children but describes being currently pregnant.	4
Indeterminate.	3
Mentions previous loss of a child.	2
More than two adults and at least one child in the household but does not explicitly indicate multigenerational / extended family living in household.	2
Mentions living in a mixed ethnicity and religion household.	1

Please select all options that apply to you:

ANSWER GROUP	RESPONSE	FREQUENCY

1	I have a long term physical or mental health condition	55
2	I have a disability	15
3	I am neurodivergent	39
4	I am a carer	22
5	I serve in the armed forces/my partner serves in the armed forces	6
	If you would like to share more information about any of these things, please add it here	23

The further information shared was as follows:

RESPONSE	ANSWER GROUPS SELECTED
CPTSD and autism.	1,3
Birthing plan ignored. Previous sexual assault experiences meant they requested no student nurses or male HCP. Asked during labour if student nurses could watch and was seen by 3 men. Felt exposed and found it triggering. Does not feel safe and lacks trust in HCPs now. Wanted notes after birth but was not given access to them.	0*
Long history of depression and anxiety.	1
History of depression and anxiety stemming from childhood sexual abuse and childhood/family trauma. History of PTSD. Carer for two children (autism and amputee).	1,4
Partner and son diagnosed with autism.	0*
Expressed a desire for further staff training on neurodiversity, and for their input to be respected.	3,4
Undiagnosed autism and ADHD. Family history of diagnoses.	3
History of depression and anxiety.	1,3
Chronic pain.	1
Depression and anxiety. Awaiting diagnosis of autism and ADHD.	3
Inflammatory bowel disease.	1
Neurodivergent, anxiety, PTSD. Carer for neurodivergent child.	1,3,4
Scoliosis	1
None	0*
Type 1 diabetes but does not consider this a disability. Short-sighted which affected birth as wearing glasses was difficult.	0*
Partner was in the armed forces but has left.	5
History of depression, anxiety, and PTSD.	1
Non-pregnant mother has autism. Commended HCP for making reasonable adjustments for "sensory overload issues" as it was recorded in their birth plan.	1,2,3
PTSD from previous birth experience.	1,2
Carer for neurodivergent wife in social situations.	4
Haemorrhaged after delivery despite HCPs knowing they were high risk.	0*
Paper notes with first child and digital notes with second child. Would have liked access to notes from first pregnancy during second to compare.	0*
Generalised anxiety disorder, treated with medication.	1

*0 has been used as the answer group when the respondent shared further information but did not select any of the response options above.

3.2 Easy Read

3.2.1 Easy Read Analysis – Overview

Nine participants responded to the Easy Read pathway of the survey. All available information and responses were analysed, although some questions were unanswered by respondents.

Five participants were family members that supported people who used maternity services, two participants indicated that English was not their first language, one participant was autistic, and one participant had a learning disability. No participants indicated that they were a support worker, had a physical disability, had sensory needs, or had a long-term health condition.

When asked if their maternity team knew enough about them to provide them and their baby the best care, five participants said yes, with one participant commenting that they were helpful. Four participants indicated that they were not sure, with one participant saying that that digital information about them was not being shared between trusts using different computer systems.

When asked if they spoke to somebody in the NHS about what was important to them in their pregnancy and how they would like to be supported, three participants said they were not sure, one participant said no, and four participants said yes. Of the participants that said yes, one explained that they spoke to a consultant midwife about their needs and wishes for their birth, whilst another participant said that they had a good plan in place until complications with the pregnancy occurred.

Two participants indicated that NHS staff listened to and supported them in a way that worked well for them, whilst three indicated that this only happened sometimes. Of these three, one participant (a family member) spoke about how there was little support for the family during a crisis, whilst another participant spoke about professionals being "incredibly unaccommodating" in some situations.

Two participants said that the NHS gave them information that was easy for them to understand. One participant indicated that this was only provided sometimes, with a specific area relating the pregnancy having little information shared with them. Another participant said no, as they were given leaflets to take away and read but they were not in an accessible format.

3.2.2 Easy Read Analysis – Question Responses

Have you or the person you support used maternity services?

ANSWER CHOICES	RESPONSES
Yes	11 (92%)
No	1 (8%)
Total Respondents	**12**

Please select from the options below - you can select more than one.

ANSWER CHOICES	RESPONSES
I am a family member	5 (56%)

English is not my first language	2 (22%)
I have a learning disability	1 (11%)
I am autistic	1 (11%)
I am a support worker	0 (0%)
I have a physical disability	0 (0%)
I have sensory needs	0 (0%)
I have a long term health condition	0 (0%)
Total Respondents	**9**

Did the maternity team know enough about you to give you and your baby the best care?

ANSWER CHOICES	RESPONSES
Yes	5 (56%)
No	0 (0%)
I'm not sure	4 (44%)
Total Respondents	**9**

Please tell us more about this.

One respondent that selected 'Yes' commented that they were helpful. This respondent indicated that they are a family member.

One respondent that selected 'I'm not sure' explained that digital information about them was not being shared between trusts using different computer systems. This respondent indicated that they are autistic.

Did you talk to somebody in the NHS about what was important to you during your pregnancy and how you like to be supported?

ANSWER CHOICES	RESPONSES
Yes	4 (50%)
No	1 (13%)
I'm not sure	3 (38%)
Total Respondents	**8**

Please tell us more about this.

One respondent that selected 'Yes' explained that they had a good plan in place until complications with the pregnancy occurred. This respondent indicated that they are a family member.

One respondent that selected 'Yes' explained that they spoke to a consultant midwife about their needs and wishes for their birth. This respondent indicated that they are autistic.

Did NHS staff listen to you and support you in a way that worked well for you?

ANSWER CHOICES	RESPONSES
Yes	2 (40%)
No	0 (0%)
Sometimes	3 (60%)
Total Respondents	**5**

Please tell us more about this.

One respondent that selected 'Sometimes' explained that there was little support for the family during a crisis. This respondent indicated that they are a family member.

One respondent that selected 'Sometimes' explained that staff were "incredibly unaccommodating" with "no consideration at all" in some situations. For example, when they were asked to come in for a scan and then told that they could not leave to look after their other children who had been left at school. This respondent indicated that they are autistic.

Did the NHS give you information that was easy to understand, for example by explaining things to you or giving you information in easy read or on video?

ANSWER CHOICES	RESPONSES
Yes	2 (40%)
No	1 (0%)
Sometimes	1 (60%)
Total Respondents	**4**

Please tell us more about this.

One respondent that selected 'Sometimes' indicated that little information was shared with them regarding a specific area relating the pregnancy. This respondent indicated that they are a family member.

One respondent that selected 'No' indicated that they were given leaflets to take away and read but they were not in an accessible format. This respondent indicated that they are autistic.

3.3 Maternity Professionals

3.3.1 Maternity Professionals Analysis – Overview

The professionals' survey sought to elicit views about all the new models of care to be incorporated into DMRSv2. A total of 200 professionals from a wide range of disciplines participated in the survey. Most professionals that responded were midwives (32%), obstetricians & gynaecologists (18%), and specialist midwives (17%). Other professionals include physiotherapists, GPs, psychologists, programme managers, and public health experts. Some of the participants were non-clinical staff such as policy makers and prison staff.

Questions asked of professionals via the survey sought feedback on the new models of care which had been drafted. If they were not satisfactory, participants were asked to make suggestions about how the models could be enhanced.

For each new model of care, most professionals reported that the information shown was relevant and adequate to provide the needed care for maternity service users. However, most respondents indicated that they were 'Unsure' (48%) whether the standard captures all the information needed to support the requirements of Under 18s, compared to 38% that indicated that it was adequate. 15 respondents made suggestions on how to ensure the requirements for the under 18s are met by the standard. This included adding details of supportive people who are above 18 years (as they may still be vulnerable and require support), details of a partner, parents (legal guardian or parent), and their immigration status. Others advised that the standard should have signposts for referrals, and that those without safeguarding concerns should have access to wider support, such as an early help support worker.

The frequency of respondents that indicated that the existing standard was not suitable for each model of care was as follows:
- Personalised care and support plan (PCSP) (n=33)
- Shared decision making (n=32)
- Maternal medicine (n=28)
- Health inequalities (n=27)
- Continuity of carer (n=25)
- Perinatal mental health (n=20)
- Fetal medicine (n=16)
- Under 18s (n=15)
- Bereavement and loss (n=13)

When asked whether PRSB's PCSP meets the diverse needs of maternity service users, of 163 respondents, 48% indicated that it did, 31% were unsure, and 20% indicated that it did not. Common themes for those that explained why it did not include: a need for access by members of multidisciplinary teams; inaccessible to those without access to technology; and a requirement the first language of the woman to be recorded, as well as whether English is a second language. Some also pointed out that the PCSP was lengthy and may defy the aim of the standard.

Of 137 respondents, 46% agreed that PRSB's Shared Decision Making Standard met the needs of recording informed decision making for the service, whilst 31% were unsure and 23% believed it did not. Several professionals highlighted that the term 'problem list' was not appropriate language. Additionally, it was highlighted that they are not involved in decision making as this is the task for the woman, but instead explained they were there to provide information about care so suggested it be renamed 'informed decision making'.

Of 121 respondents, 53% agreed that the standard captured all the necessary details to record information about maternal medicine, 24% were unsure, and 23% indicated that it did not. Respondents indicated that the standard should capture mental health history, and that the history should focus on risk factors for developing medical problems during pregnancy. Other suggested changes included a request for information on alcohol consumption to help identify fetuses at risk of fetal alcohol spectrum disorders (FASD), and documentation on vaccination status.

Of 119 respondents, 52% agreed that the standard captured all the necessary details to record information about feta medicine, 34% were unsure, and 13% indicated that it did not.

Explanations on why it did not were generally repeated from the maternal medicine question, though other suggestions included parental concerns / thoughts / wishes, and the ability to capture chorioinicity for multiple pregnancies.

49% of 117 respondents agreed that the information in the standard was adequate for capturing details of midwifery continuity of carer, with 29% unsure and 21% indicated it is not adequate. One suggestion was that space was needed to record changes in MCoC teams, including the student midwives and those whose roles sat outside maternity services but who also provide care. Another suggestion included capturing the reason for discontinuation of MCoC.

60% of 116 respondents indicated that the standard captures the relevant details to support bereavement and loss in maternity, 28% were unsure, and 11% believed it did not. Similar to contributions from the professional webinars and public workshops, professionals advised that the bereavement and loss standard should be more patient focused to be able to identify any underlying mental health concerns. Other suggestions include capturing information about the type of loss and plans for future pregnancy.

Of 112 respondents, 53% indicated that the standards captured all necessary details to record information about perinatal mental health, 29% were unsure, and 18% indicated that it did not. Common suggestions for improvement included an element for how mental health needs may impact birth, family / maternal mental health history, and information about challenging social circumstances.

54% of 110 respondents reported that the information shown in the standard could support reduction of risk of health inequalities, although 22% were unsure whether it could and 25% believed it could not. Suggestions for improvement included the need flag whether there was a language barrier for the woman, including a reasonable adjustment flag. It was suggested that it should also include information about whether the woman is a care leaver or armed forces personnel.

All suggested elements to monitor data for perinatal pelvic had ≥ 50% of 109 respondents indicating that it would be beneficial to include in the standard. The elements with the most respondents agreeing that it would be beneficial were history of obstetric anal sphincter injury (OASI) (78%), urinary/faecal incontinence (76%), and tear/episiotomy sustained during previous or current birth (76%). Additional suggestions made by respondents included pain during sexual intercourse, other comorbidities, who provided care for pelvic floor health, and birth position.

Respondents had the opportunity to provide further comments about the proposed Digital Maternity Record Standard at the end of the survey. Comments included concerns around the language used in the standard, concerns about implementation being challenging, and the need to link to the neonatal / baby record.

3.3.2 Maternity Professionals Analysis – Question Responses

Please select your profession or job title

ANSWER CHOICES	RESPONSES
Nurse	2 (1%)
Specialist nurse	0 (0%)
Midwife	64 (32%)

Specialist midwife	34 (17%)
Health visitor	3 (2%)
Clinical support worker or healthcare assistant	1 (<1%)
Radiographer	0 (0%)
Physiotherapist	4 (2%)
Dietitian	0 (0%)
Other allied health professional	1 (<1%)
Psychologist	5 (3%)
Pharmacist	0 (0%)
Other scientific or therapeutic role	1 (<1%)
Ambulance staff	0 (0%)
Non-clinical staff	11 (6%)
Doula or other independent practitioner	1 (<1%)
Doctor - Obstetrics/Obstetrics and Gynaecology	35 (18%)
Doctor - Gynaecology	1 (<1%)
Doctor - Anaesthetist	2 (1%)
Doctor - Physician	1 (<1%)
Doctor - Psychiatrist	2 (1%)
Doctor - Neonatal	1 (<1%)
Doctor - GP	3 (2%)
Doctor - other (please specify below)	1 (<1%)
Other (please specify)	27 (14%)
Total Respondents	**200**

The respondent that selected 'Doctor – other (please specify below)' did not specify their profession further.

Two respondents who selected 'Other (please specify)' listed their professions as Doula and Psychiatrist, which are already included as separate response options. Consequently, these responses were reallocated from the 'Other (please specify)' category to the appropriate profession categories, resulting in an adjusted total of 27 responses for 'Other (please specify)'. The other professions / job titles specified are below.

ANSWER CHOICES	RESPONSES
Clinical Academic Public Health Consultant	2 (7%)
Digital Midwife	2 (7%)
Maternity and Neonatal Voices Partnership Lead	2 (7%)
Public Health Specialist	2 (7%)
Analyst	1 (4%)
Clinical Safety Officer and Health Visitor	1 (4%)
Clinical Systems Designer	1 (4%)
Chief Nursing Informatics Officer (CNIO)	1 (4%)
Commissioning Manager	1 (4%)
Dataset Developer	1 (4%)
Digital Project Manager	1 (4%)
Digital Transformation Midwife	1 (4%)

Doula & Maternity and Neonatal Voices Partnership Chair	1 (4%)
MBRRACE-UK Researcher	1 (4%)
Mellow Bumps Practitioner	1 (4%)
Midwife Academic / Researcher	1 (4%)
Programme Manager for an Integrated Care System	1 (4%)
Public Governor NHS Trust	1 (4%)
Quality Improvement (QI) Manager	1 (4%)
Retired GP	1 (4%)
Student Midwife	1 (4%)
Vaccination Programme Manager	1 (4%)
Total Respondents	**27**

If you have a particular specialty, interest, or focus to your practice, please share this with us here.

PROFESSION/JOB TITLE	SPECIALITY	RESPONSES
Analyst	Tobacco dependence	1
Clinical Academic Public Health Consultant	Preconception health, inequalities, contraception, pregnancy planning	1
Dentist	Primary and secondary care dentistry	1
Doctor - Anaesthetist	Obstetrics	1
Doctor - Obstetrics/Obstetrics and Gynaecology	Maternal medicine	3
	Abortion care	1
	Clinical informatics	1
	Early pregnancy and Acute gynaecology and intrapartum care	1
	Labour ward and fetal monitoring lead	1
	Maternal medicine and high-risk obstetrics	1
	Obstetrics	1
	Perinatal mental health	1
	Teenage pregnancy	1
Doctor - Other	Critical care and anaesthesia, particularly enhanced maternal care	1
Doctor - Physician	Maternal medicine	1
Doctor - Psychiatrist	Transfer of information from Maternal notes to child in keeping with FASD NICE QS 2	1
Doula & Maternity and Neonatal Voices Partnership Chair	Inclusive language	1
Health Visitor	Caesarean care	1
	Perinatal and infant mental health	1
Midwife	Community midwifery	2
	Antenatal and postnatal care- particularly safeguarding	1
	Clinical informatics	1
	Clinical systems midwife and IM&T change manager	1

	Community - Home Birth - Continuity - Communication between MDTs - OOG Care Plans	1
	Digital health	1
	Digital maternity	1
	Equality, diversity, and inclusion	1
	Enhanced and critical care of ill women during or following pregnancy	1
	IT	1
	Multiple pregnancy, fetal medicine	1
	Personalised care	1
	Policy development clinical practice standards	1
	Research midwife / community midwife	1
	Transformation programme postnatal, smoking, infant feeding	1
Midwife Academic/ Researcher	Multiple births	1
Non-clinical staff	Alcohol and pregnancy	1
	Antenatal and newborn screening	1
	Armed forces	1
	Digital	1
	Reasonable adjustments	1
	Social prescribing link work	1
Nurse	Inclusion health	1
Other scientific or therapeutic role	Screening	1
Physiotherapist	Pelvic health	1
	Pelvic health, obstetrics, and gynaecology	1
	Women's health	1
Programme Manager for an Integrated Care System	Pelvic health	1
Psychologist	Clinical psychologist who works within Maternal and Perinatal Mental Health Services and representing the British Psychological Society Perinatal Faculty	1
	Perinatal mental health	1
	Perinatal psychology	1
Public Health Specialist	Public health intelligence, population health surveillance, health improvement for child and maternal health	1
	Public health intelligence, preconception health and care, population health surveillance, health improvement	1
QI Manager	Maternity and neonatal	1
Specialist Midwife	Digital midwife	6
	Antenatal and newborn Screening	2
	Transformation	2
	ANC manager and maternity and children's governance lead for screening	1
	Clinical informatics	1

	Clinical Research delivery	1
	Consultant midwife, responsible for implementing PCSP	1
	Digital and data	1
	Digital transformation	1
	Education and training	1
	Fetal wellbeing	1
	LMNS senior digital midwife	1
	Long-term conditions	1
	Maternal medicine	1
	Maternity	1
	Pelvic health	1
	Prevention / transformation	1
	Public health, obesity, smoking cessation, planned pregnancy/contraception	1
	Quality and safety	1
	Smoking cessation	1
Vaccination Programme Manager	Vaccinations	1
Total Respondents		**85**

What care setting are you usually based in?

ANSWER CHOICES	RESPONSES
Hospital	115 (58%)
Community	23 (12%)
Mental health	5 (3%)
General practice	4 (2%)
Other (please specify)	53 (27%)
Total Respondents	**200**

The other settings are specified are below.

ANSWER CHOICES	RESPONSES
ICB	7 (13%)
Office	6 (11%)
NHSE	5 (9%)
Hospital and community	4 (8%)
LMNS	4 (8%)
DHSC	2 (4%)
IT / digital	2 (4%)
Maternity	2 (4%)
Public health / academia	2 (4%)
QI	2 (4%)
All listed	1 (2%)
Charity	1 (2%)
Dental practice	1 (2%)
Higher education / research centre	1 (2%)
Hybrid	1 (2%)

LMNS and ICB	1 (2%)
National	1 (2%)
Online education	1 (2%)
Prison	1 (2%)
Professional	1 (2%)
Public health	1 (2%)
Quality Assurance (QA)	1 (2%)
Region	1 (2%)
Regional and community	1 (2%)
Research	1 (2%)
Social services	1 (2%)
Unverifiable	1 (2%)
Total Respondents	**53**

Does the PRSB's Personalised Care and Support Plan Standard meet the diverse needs of all groups that use maternity services?

ANSWER CHOICES	RESPONSES
Yes, it does	79 (48%)
Don't know/unsure	51 (31%)
Prefer not to say	0 (0%)
No, it does not (please explain)	33 (20%)
Total Respondents	**163**

The explanations provided by those that responded 'No, it does not' were analysed for themes. The table below shows each theme, as well as the number of respondents who mentioned the theme.

THEME FROM RESPONSE	RESPONSES MENTIONING THEME
Needs to be accessible / interoperable for use by multidisciplinary teams and be able to capture their roles.	6
Inaccessible to families/women who do not have access to technology therefore does not fit the term 'personalised' as it not owned by the person	3
Language needs should include mother tongue and English as second language.	3
Needs to capture country of birth, ethnicity, gender identity/assigned at birth.	3
Reason is unclear.	3
The standard requires enhancement to include both physical and mental health needs, and a flag to indicate previous baby loss and reasonable adjustments.	3
Difficult to access and read quickly, too long so will miss the point.	2

Does not capture armed forces personnel.	1
Does not understand the question.	1
More explanations about the "About Me" section.	1
Needs risk factors, perinatal mental health, and clinical information.	1
No dental care included.	1
Questioning why care and support plans are separate to additional care and support plan.	1
The decisions are entirely the service users, and this does not give the weight, which is legally bound to the service user, whether or not they wish to discuss with their clinician.	1
There does not appear to be anywhere within the 'care and support plan' section that guides women to think about specific parts of their pregnancy, labour, and birth that they may need to make informed decisions.	1
Trusts still rely on paper notes.	1
Vaccinations status, vaccinations required and given in pregnancy.	1

Feedback from our consultation so far has indicated that good personalised care and support plans are already being used. If you have a good one that you would like us to consider in our analysis, please upload a blank copy here.

8 respondents shared personalised care and support plans with PRSB via this question.

Shared decision making is an integral part of the Personalised Care and Support Plan. The PRSB's existing Shared Decision Making Standard V0.6 should capture the data requirements for informed decision making in maternity. Does this standard meet the needs of recording informed decision making in maternity services?

ANSWER CHOICES	RESPONSES
Yes, it does	63 (46%)
Don't know/unsure	42 (31%)
Prefer not to say	0 (0%)
No, it does not (please advise what could be added to make it more suitable for use in maternity settings)	32 (23%)
Total Respondents	**137**

The explanations provided by those that responded 'No, it does not' were analysed for themes. The table below shows each theme, as well as the number of respondents who mentioned the theme.

THEME FROM RESPONSE	RESPONSES MENTIONING THEME
Problem list should be re-worded.	5

Reason is unclear.	3
Shared decision making and informed decision making are two separate philosophies.	3
Use tools such as BRAIN instead of including full consent forms.	3
English as second language, interpreter services, more language options.	2
Information is fine; however, they question how interoperability will be implemented across Trusts and Systems.	2
Issues of coercion from consultants towards the women.	2
Should be enhanced using the trauma-informed care.	2
Should include links to resources and information formats should be suitable for unbiased decision making.	2
There should be professional recommendations (professional only plan), patient's wishes (patients plan), and then the agreed shared decision plan.	2
Capture when the woman declines any service provided.	1
Lengthy.	1
Questioning what the problem list includes, and whether it includes dental care.	1
Record of capacity as part of the decision making.	1
Should include beliefs of the woman.	1
Unsure what this looks like in a clinical record there needs to be an agreed standard for the structure of electronic records.	1

The information detailed here and summarised below plays an important part in shaping the whole standard for maternity services, including maternal medicine. Does this information capture all the necessary details to record information about maternal medicine?

ANSWER CHOICES	RESPONSES
Yes, it does	64 (53%)
Don't know/unsure	29 (24%)
Prefer not to say	0 (0%)
No, it does not (please advise what changes should be made)	28 (23%)
Total Respondents	**121**

The explanations provided by those that responded 'No, it does not' were analysed for themes. The table below shows each theme, as well as the number of respondents who mentioned the theme.

THEME FROM RESPONSE	RESPONSES MENTIONING THEME
Reason is unclear.	5
Should capture prior mental health history, feelings, and wishes.	5
History should be focused on risk factors for developing medical issues in the pregnancy.	3
Information on smoking status not included.	2
Lack of information on alcohol consumption which helps to identify fetus that may be at risk of FASD.	2
Problem list should be reworded.	2
Documentation of vaccinations received/refused.	1
Does not capture standard pregnancy risks.	1
For screening it would be helpful to capture what tests were offered, which were accepted and declined, as well as those requested, and results.	1
Other personnels are not captured like the armed forces.	1
Should include genetic testing and counselling.	1
There is a different section for care and support plans and additional support plans. Plans should be holistic and not documented in different sections for different events.	1
Unsure if it links to the reasonable adjustment digital flag and the NHS spine.	1
We cannot see maternity notes now so cannot assess risk and integrate important data effectively.	1

The information detailed here and summarised below plays an important part in shaping the whole standard for maternity services, including fetal medicine. Does this information capture all the necessary details to record information about fetal medicine?

ANSWER CHOICES	RESPONSES
Yes, it does	62 (52%)
Don't know/unsure	41 (34%)
Prefer not to say	0 (0%)
No, it does not (please explain)	16 (13%)
Total Respondents	**119**

The explanations provided by those that responded 'No, it does not' were analysed for themes. The table below shows each theme, as well as the number of respondents who mentioned the theme.

THEME FROM RESPONSE	RESPONSES MENTIONING THEME
Repeated suggestions.	4
Reason is unclear.	2

Should capture treatments refused, risk factors.	2
Should include genetic testing and counselling.	2
Birth details not captured.	1
Care plan and additional support are captured separately.	1
Interoperability issues.	1
Needs parental thoughts / wishes / concerns.	1
Should be made concise to enable proper care plan.	1
Should capture chorionicity in multiple pregnancy as this determines the care plan.	1

Does the information detailed here and summarised below cover all the necessary details to capture continuity of carer in maternity services?

ANSWER CHOICES	RESPONSES
Yes, it does	57 (49%)
Don't know/unsure	34 (29%)
Prefer not to say	1 (>1%)
No, it does not (please explain)	25 (21%)
Total Respondents	**117**

The explanations provided by those that responded 'No, it does not' were analysed for themes. The table below shows each theme, as well as the number of respondents who mentioned the theme.

THEME FROM RESPONSE	RESPONSES MENTIONING THEME
Digital documentation will have to ensure each person making an entry has their name digitally recorded to track continuity of carer.	6
Continuity of carer is adequate but needs to capture the reasons for a discontinued continuity of carer, like retirement of midwife.	3
It is relevant to have continuity of carer for vulnerable patients and specific clinics not just midwives.	3
Unclear reason.	3
Adequate but requires enhancement so that it is not just a tick box but reflect dynamic individualised conversations though with the same professional.	2
Needs to document the lead carer.	2
As there are only a few trusts providing continuity of carer I don't see this section as relevant.	1
Does not include scope for student midwives	1
In the event continuity of carer cannot be contacted, it is important to include the necessary details: - Risks - Current medication – Allergies.	1
Needs to capture appointment location.	1
Not sure if it includes intrapartum care	1
Questioning whether the data will be useful for audits.	1

Does the following information (which matches the requirements from the national bereavement care pathway) capture all the essential Digital Maternity Record Standard survey details to support bereavement and loss in maternity?

ANSWER CHOICES	RESPONSES
Yes, it does	70 (60%)
Don't know/unsure	32 (28%)
Prefer not to say	1 (>1%)
No, it does not (please explain)	13 (11%)
Total Respondents	**116**

The explanations provided by those that responded 'No, it does not' were analysed for themes. The table below shows each theme, as well as the number of respondents who mentioned the theme.

THEME FROM RESPONSE	RESPONSES MENTIONING THEME
Should include information about type of loss, Postmortem and future pregnancy planning.	2
Should include support from partner or local peer support.	2
Space needed for woman to document feelings about loss.	2
Bereavement named midwife would be a good addition.	1
Duplicated responses.	1
Require training.	1
Should capture main patient concerns even though may be repetitive but allow professional to address underlying anxieties at each contact.	1
Should include a check list to ensure all relevant professionals have been informed about loss.	1
Unclear response.	1

Does the information detailed here and summarised below capture all the necessary details to record information about perinatal mental health?

ANSWER CHOICES	RESPONSES
Yes, it does	59 (53%)
Don't know/unsure	33 (29%)
Prefer not to say	0 (0%)
No, it does not (please explain)	20 (18%)
Total Respondents	**112**

The explanations provided by those that responded 'No, it does not' were analysed for themes. The table below shows each theme, as well as the number of respondents who mentioned the theme.

THEME FROM RESPONSE	RESPONSES MENTIONING THEME
Add a prompt or section about how mental health needs may relate or impact womens' feelings about birth	4
Unclear reason	3
Family and Maternal mental health history	2
Information about debt/financial challenges, access to transport, literacy, smoking status	2
Information about partner and carers support needs	2
It relies on diagnosed perinatal mental health history and as many service users do not/cannot access appropriate care pathways for this, detail gathered from the service user about non-diagnosed concerns should be able to be documented too	2
Should include space for recording advice, including advice on where to access support, given (mothers frequently are given conflicting advice by professionals and so all advice given should be recorded)	2
Which team are they under - need contact details for PMHCS, CMHT etc	2
No mention here of any proposed standard of maternity assessment for mental health. i.e. GAD	1

Do the existing equality and diversity information items summarised below accurately capture all the characteristics and key information that could help reduce the risk of people experiencing health inequalities?

ANSWER CHOICES	RESPONSES
Yes, it does	59 (54%)
Don't know/unsure	24 (22%)
Prefer not to say	0 (0%)
No, it does not (please explain)	27 (25%)
Total Respondents	**110**

The explanations provided by those that responded 'No, it does not' were analysed for themes. The table below shows each theme, as well as the number of respondents who mentioned the theme.

THEME FROM RESPONSE	RESPONSES MENTIONING THEME
Language barrier.	6
Reasonable adjustment flag.	3
Needs to include care leavers, personnel of armed forces.	2
Should be able to flag women with multiple characteristics and their needs as a result of the characteristics.	2

To have a non-judgemental communication.	2
To include country of birth.	2
Unclear advice.	2
Duplicated advice.	1
Not detailed enough.	1
Plans to obtain equity - e.g. travel to clinic or in labour, childcare plans barriers to engaging with healthcare agencies involved.	1
Risk assessments identifying cohorts as high risk for pre-term birth.	1
Sexual orientation would be better as an independent category. Information about the non-birthing parent should also avoid heteronormative language.	1
Should be implemented at the grass root level.	1
Should include communication needs to disabled persons.	1
To have an 'inclusion midwife' in the team.	1

The Digital Maternity Record Standard allows a person's age and any safeguarding concerns to be recorded. Does the standard capture all the information needed to support the unique requirements of women and birthing people under the age of 18?

ANSWER CHOICES	RESPONSES
Yes, it does	42 (38%)
Don't know/unsure	53 (48%)
Prefer not to say	0 (0%)
No, it does not (please explain)	15 (14%)
Total Respondents	**110**

The explanations provided by those that responded 'No, it does not' were analysed for themes. The table below shows each theme, as well as the number of respondents who mentioned the theme.

THEME FROM RESPONSE	RESPONSES MENTIONING THEME
Additional forms are currently needed to fulfill actions needed for those under 18. A digital system that signposts to the additional requirements would be beneficial and a flag for reasonable adjustment.	3
Details of parents/ adopted parents/legal guardian and immigration status should be included.	3
A wider support group will be needed for under 18s who do not require safeguarding. e.g. early help, youth worker.	1
Details of partner, and whether involved or not.	1
Does information support other vulnerable groups and other ages?	1

Inability to access the information in this section in some practices.	1
It may not be appropriate to share all safeguarding concerns.	1
Needs to be reviewed with experts in the field.	1
Should look at the separate MARAC for under 18s.	1
Unclear advice.	1
Whole family plans, education, accommodation, specialist midwife, support groups.	1

Which of the following data elements would be beneficial to include in the standard when capturing monitoring data for perinatal pelvic floor health?

ANSWER CHOICES	RESPONSES
Assessment result	70 (64%)
Information and advice given about pelvic health	80 (73%)
Compliance with information and advice given about pelvic health	54 (50%)
Urinary/faecal incontinence	83 (76%)
Urgency of bowel/bladder use	81 (74%)
Tear/episiotomy sustained during previous or current birth	83 (76%)
Forceps used in previous birth	76 (70%)
Current pregnancy birth details	72 (66%)
Exercise programme prescribed	72 (66%)
Referral details	72 (66%)
History of prolapse	81 (74%)
Pelvic/vaginal pain	77 (71%)
History of obstetric anal sphincter injury (OASI)	85 (78%)
I don't know/unsure	23 (21%)
Other (please specify)	16 (15%)
Total Respondents	**109**

The explanations provided by those that responded 'Other (please specify)' were analysed for themes. The table below shows each theme, as well as the number of respondents who mentioned the theme.

THEME FROM RESPONSE	RESPONSES MENTIONING THEME
Pain during sex, Any other comorbidities.	2
Who provided care for pelvic floor health i.e physiotherapist, midwife, Obstetricians, Name of lead women's health physiotherapist.	2
Birth Position.	1
Compliance is difficult because non-maternity staff like physiotherapists will provide care, however, they don't use maternity systems.	1

Details of management and follow up by gynecologist when indicated.	1
Emotional distress or mental health needs related to traumatic childbirth (e.g., PTSD).	1
Pregnancy sickness and whether that is having an impact on pelvic floor (many women won't mention this in 1st pregnancy due to embarrassment).	1
Risk factors for pelvic floor dysfunction BMI etc.	1
Self-referral option.	1
The national self-assessment pelvic health tool is being produced and is due to be available Autumn 2024. This will include risk factors and symptoms (some of which are mentioned above). Being able to have the tool embedded with an interpretation score would be transparent and support patients with staff fully understanding their risk. The interpretation of this is underway with a national working group.	1
Use of language is important to ensure compliance.	1

Thank you for making time to take part in our survey. If you have any further comments about the Digital Maternity Record Standard information model, please share them below.

THEME FROM RESPONSE	RESPONSES MENTIONING THEME
Concerns around language used. E.g., language from Re:Birth, person-centred language, language that does not imply ill-health.	3
Concerns around implementation being challenging.	1
Consider digital inclusion.	1
Expression of gratitude.	1
Inclusion of health status and health promoting behaviours of the woman before pregnancy.	1
Information needs to be provided in multiple languages.	1
More emphasis needed on wound care.	1
Needs to account for personalisation.	1
Needs to link to neonatal / baby record.	1
Public health needs should be included	1
Queries around timescale.	1
Queries around training to use the standard.	1
Query around lack of inclusion of dental care.	1
Query around linking to reasonable adjustment digital flag via NHS Spine.	1
Requires integration with existing systems.	1
Standard is satisfactory.	1

3.4 Maternity System Suppliers

3.4.1 Maternity System Suppliers Analysis – Overview

Ten participants, representing several of the UKs biggest maternity and general practice system suppliers engaged with this survey. Although several responses were incomplete, all the available information has been analysed.

At least 50% of all respondents indicated that the following would be useful in assisting the implementation of DMRS Release 2:

- Standardisation of front-end workflow assessments/scores/questionnaires (100%)
- Technical specifications (FHIR) (100%)
- Implementation toolkit (90%)
- Examples of populated FHIR messages (80%)
- Release notes (including new implementation requirements for DMRS Release 2) (70%)
- Integration between the DMRS and Maternity Services Dataset (70%)
- Use cases (60%)
- Entity relationship diagram (60%)
- Examples (50%)

One respondent added that a clearly defined scope for Release 2 would be helpful, with confirmation that it will cover interoperability elements.

When asked about the amount of adaptation supplier's systems would need to implement the new elements of DMRS Release 2, there was a variety of responses with some requiring zero, through to major changes from the five respondents to this question.

Four suppliers indicated that their system had a patient/service user portal, and one respondent indicated they had one in development. The rest of the respondents skipped this question. Of these respondents:

- Three applications have or will have integration with other health apps, including login with NHS login, and the ability to display at least part of the maternity record to the service user.
- Two have or will have the capability to push information out to the service user.
- One will have the ability to allow patient to add to their own notes.

Additional capabilities include contact with care providers, creation of individualised care plans, and scheduling appointments. Three respondents described the information shared with service users in the person's maternity record which included test results, diagnoses, appointments, visit summaries, notes, or aim to share all information apart from safeguarding information.

Suppliers were provided with a link to the draft information at the start of the survey to review, and space at the end of the survey to provide any further comments they had about the draft information model. No respondents used this space to make any further comments.

Feedback from suppliers highlights their priorities when adopting DMRS Release 2, which includes standardised workflows, FHIR specifications, and an implementation toolkit. This data gathered from suppliers helps inform the PRSB about the deliverables that can be produced to aid adoption. This is why this release includes provide the following to aid in implementation:

- An overview of the changes from DMRS Release 1 to Release 2.
- Coordination between DMRS and the Maternity Services Dataset to ensure. interoperability of data elements.
- Use cases
- A populated example.
- An Entity Relationship Diagram.

The front-end workflow, standardised clinical assessment documents, risk and screening tools, clinical questionnaires, or the production of implementation toolkits falls outside the scope of this project.

PRSB will also recommend that NHSE develop a FHIR specification including examples of populated FHIR messages to aid implementation.

3.4.2 Maternity System Suppliers Analysis – Question Responses

Which system supplier organisation do you work for or represent?

SYSTEM SUPPLIER	RESPONSES
Dedalus	3
Magentus	2
Epic Systems	1
Nerve Centre	1
PRSB	1
System C	1
Vision	1
Skipped Question	4

What would be useful for NHS England or the PRSB to provide to assist you in implementing the Digital Maternity Record Standard (DMRS)?
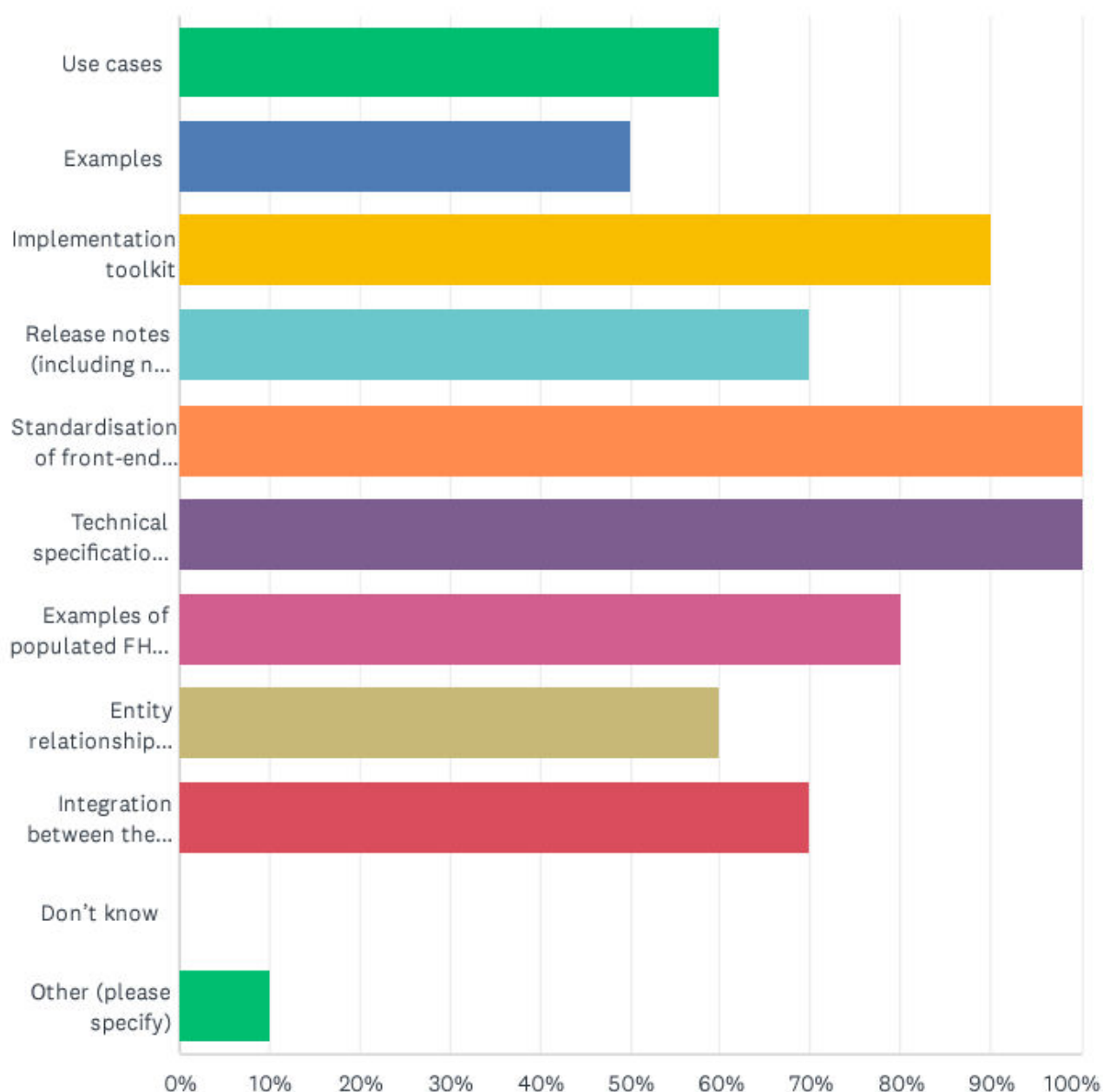
- 100% of 10 respondents selected:
    - Standardisation of front-end workflow assessments / scores / questionnaires
    - Technical specifications (FHIR)
- All options had at least 50% agreement
- 1 additional suggestion to confirm that Release 2 will cover interoperability elements.

The DMRS should be used with several other PRSB standards, including the Personalised Care and Support Plan Standard, the Informed Decision Making Standard and the About Me Standard to support the new models of maternity care. What changes do you need to make in you system to implement the following?

ANSWER CHOICES	NO CHANGES	MINOR CHANGES	MAJOR CHANGES	DON'T KNOW	TOTAL
Personalised care and support plan	0 (0%)	3 (60%)	2 (40%)	0 (0%)	5
Informed decision making	0 (0%)	3 (60%)	2 (40%)	0 (0%)	5
About me	0 (0%)	3 (60%)	2 (40%)	0 (0%)	5

Problem list	1 (20%)	2 (40%)	2 (40%)	0 (0%)	**5**
Smoking record	1 (20%)	2 (40%)	2 (40%)	0 (0%)	**5**
Formulation	0 (0%)	2 (40%)	2 (40%)	1 (20%)	**5**
Future appointment	3 (60%)	1 (20%)	1 (20%)	0 (0%)	**5**
Clinical narrative	3 (60%)	1 (20%)	1 (20%)	0 (0%)	**5**
Professional contacts	3 (60%)	1 (20%)	1 (20%)	0 (0%)	**5**
Labour and birth	0 (0%)	3 (60%)	2 (40%)	0 (0%)	**5**

Does your system have a patient/person portal that allows people to access their record?

ANSWER CHOICES	RESPONSES
We have a patient/person portal	4 (80%)
We are developing a patient/person portal	1 (20%)
We do not have a patient/person portal, but we have future plans to develop one	0 (0%)
We do not have a patient/person portal, and have no plans to develop one	0 (0%)
I don't know/unsure/prefer not to say	0 (0%)
Total Respondents	**5**

Please select all that apply to your system's patient/person portal.

ANSWER CHOICES	RESPONSES
Our patient/person portal has/will have the capability to integrate with other health apps	3 (70%)
Our patient/person portal has/will have the capability to allow users to login with their NHS login	3 (70%)
Our patient/person portal has/will have the capability to allow users to input their own notes	1 (25%)
Our patient/person portal has/will have the capability to push information and advice to the person (e.g., information leaflets)	2 (50%)
Our patient/person portal has/will have the capability to display at least part of the person's maternity record to them	3 (70%)
None of these	0 (0%)
I don't know/unsure/prefer not to say	0 (0%)
Other relevant capability (please specify)	1 (25%)
Total Respondents	**4**

The participant who selected 'Other relevant capabilities' included features such as:

- Allows patients to send messages to providers
- Allows organisations to create interactive and individualised plan of care (configuration required)
- Allows patients to schedule appointments (configuration required by trusts)

What areas of the person's maternity record are visible to them through your system? (E.g., scan reports, blood results etc.)

- 3 respondents
    - **Response 1**: Test results, diagnoses.
    - **Response 2**: Upcoming appointments, labs, imaging results, electronic maternity handheld notes (that include notes), visit summary.
    - **Response 3**: Still under development but aim is to show all notes except safeguarding information.

Thank you for making time to take part in our survey. If you have any further comments about the Digital Maternity Record Standard information model, please share them below.

One response to this question, in which the respondent indicated that it would be helpful if the standard was complementary with other national maternity drivers. This included Clinical Negligence Scheme for Trusts (CNST), Maternity Incentive Scheme (MIS), Maternity Services Data Set (MSDS), and Payment by Results (PBR).

4   Limitations

- Multiple analysts were involved in the thematic analysis, but due to time constraints, they were unable to peer review each other's work. This lack of peer review may have led to inconsistencies in the interpretation and categorisation of themes.
- Only three practising GPs responded to the survey. This small sample size is not representative of the broader GP population, which raises concerns about the generalisability of the findings.
- Misunderstanding questions was either explicitly stated by participants or inferred from their responses, indicating that certain questions were not sufficiently clear or well-designed. This lead to some answers not being interpretable.

5   Conclusions and Recommendations

The outputs from the survey were used to refine the draft information standard and inform some of the project recommendations. These are discussed further in the main body of the project final report.

6   Appendix A – Service User Questions

1. **Did the maternity team, and others who cared for you during and after your pregnancy, have all the information they needed to provide care that was right for you?** [Single select]
   - Everyone had enough information
   - Some knew everything, others had little or no information
   - They knew about most things but not always
   - They had some information but there were gaps
   - They had very little or no information
   - Don't remember
   - Please tell us more about this [Text entry]

2. **If they didn't, what impact did this have on you and your pregnancy experience? Please choose all that apply.** [Multiple select]
   - I had to repeat information multiple times to different people
   - I felt I had to be responsible for making sure information was known and shared
   - I felt worried that the people looking after me wouldn't know my needs and wishes
   - I had to do my own research into things I was told in appointments and what they meant for my options and risks in my pregnancy
   - Teams didn't always know why I was being seen or what my appointment was for
   - I have to relive traumatic experiences from previous pregnancies several times
   - Not applicable
   - Other (please share your experience) [Text entry]

3. **Did you have the same community midwife during your pregnancy?** [Single select]
   - All of the time
   - Most of the time
   - Rarely
   - Never
   - Don't remember
   - If you didn't, did the midwife make sure they knew about you from your notes, to provide the care you needed? [Text entry]

4. **How important is it to you that the people caring for you during your pregnancy know about the following?** [Matrix/Rating Scale]

	Not important	Somewhat important	Very important	Don't know	Not applicable
Physical health history	○	○	○	○	○
Mental health history	○	○	○	○	○
Previous pregnancy experiences, including complications	○	○	○	○	○
Previous pregnancy loss	○	○	○	○	○
Information about you as a person; your family and household, cultural background and identity	○	○	○	○	○
Safeguarding information	○	○	○	○	○

   - Are there other types of information that are important for your maternity team to know about you? [Text entry]

5. **Did you talk about the things listed above with a midwife to discuss, plan and make decisions about your pregnancy?** [Single select]
   - Yes, we talked about everything I wanted to
   - A little, but not as much as I would have liked

- No, not at all
- Don't remember

6. **Is there any information you would want to agree first, before it was shared with the people caring for you?** [Text entry]

7. **Were you able to see your maternity notes?** [Single select]
   - Yes, I had paper maternity notes
   - Yes, I used an app to view a digital version
   - Yes, I had both paper notes and an app
   - No, I had no access to my maternity notes
   - Don't remember

8. **How would you prefer to have your maternity notes?** [Single select]
   - In paper format
   - Using an app or online
   - Both paper and using an app
   - Neither, I don't want to see my notes
   - No preference

9. **The information I could see in my maternity notes was…** [Matrix/Rating scale]

	Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly disagree
Reflective of my needs and wishes	○	○	○	○	○
Up to date	○	○	○	○	○
Easy to understand	○	○	○	○	○
Useful to help me plan my care	○	○	○	○	○
Complete	○	○	○	○	○

   - Would anything have made your experience better? [Text entry]

10. **At the end of your pregnancy, were you able to keep a copy of your maternity notes?** [Single select]
   - Yes
   - No
   - Don't remember

11. **Did you want to keep a copy of your notes to support your postnatal care, your baby's care or future pregnancies?** [Single select]
   - Yes
   - No
   - I don't know or have no preference

12. **What did you use your maternity notes app for?** [Multiple select]
    - Adding and updating information about me or my health
    - Speaking to my midwife or doctor
    - Sharing information with my family and friends
    - Understanding my care, treatment and test results
    - Viewing appointments
    - Booking and changing appointments
    - Don't remember
    - Other (please specify) [Text entry]

13. **What would you want to be able to do using your maternity notes app?** [Multiple select]
    - Add and update information about me and my health
    - Speak to my midwife or doctor
    - Share information with my family and friends
    - Understand my care, treatment and test results
    - View appointments
    - Book and change appointments
    - Other (please specify) [Text entry]

14. **Postcode** [Text entry]

15. **Age** [Text entry]

16. **Main language** [Text entry]

17. **Gender** [Single select]
    - Male
    - Female
    - Please specify [Text entry]

18. **Is your gender identity the same as the sex you were assigned at birth?** [Single select]
    - Yes
    - No
    - Not sure
    - Prefer not to say

19. **Sexual orientation. These options reflect those used in the most recent census in 2021.** [Single select]
    - Straight/heterosexual
    - Gay or lesbian
    - Bisexual

- Please specify [Text entry]

20. **Religion. These options reflect the religions used in the most recent census in 2021.** [Single select]
- Buddhist
- Christian
- Hindu
- Jewish
- Muslim
- Sikh
- No religion
- Any other religion (please specify) [Text entry]

21. **Ethnic group. These options reflect the ethnic groups categories used in the most recent census in 2021.** [Single select]
- Asian, Asian British – Indian
- Asian, Asian British – Pakistani
- Asian, Asian British – Bangladeshi
- Asian, Asian British – Chinese
- Asian, Asian British – Any other Asian background (please specify below)
- Black, Black British, Caribbean or African – Caribbean
- Black, Black British, Caribbean or African – African
- Black, Black British, Caribbean or African – Any other Black background (please specify below)
- Mixed or multiple ethnic groups – White and Black Caribbean
- Mixed or multiple ethnic groups – White and Black African
- Mixed or multiple ethnic groups – White and Asian
- Mixed or multiple ethnic groups – Any other mixed background (please specify below)
- Other ethnic group – Arab
- Other ethnic group (please specify below)
- White – English, Welsh, Scottish, Northern Irish or British
- White – Irish
- White – Gypsy or Irish Traveller
- White – Roma
- White – Any other White background (please specify below)
- If you have selected other above, please specify here [Text entry]

22. **Describe your household. For example, the number of adults and children, whether you live you extended family etc.** [Text entry]

23. **Please select all the statements that apply to you.** [Multiple select]
- I have a long term physical or mental health condition
- I have a disability
- I am neurodivergent
- I am a carer
- I serve in the armed forces/my partner serves in the armed forces

- If you would like to share more information about any of these things, please add it here. [Text entry]

7   Appendix B – Easy Read Questions

1. **Have you or the person you support used maternity services?** [Single select]
   - Yes
   - No

2. **Please select from the options below - you can select more than one** [Multiple select]
   - I am a support worker
   - I am a family member
   - I have a learning disability
   - I am autistic
   - I have a physical disability
   - I have sensory needs
   - I have a long term health condition
   - English is not my first language

3. **Did the maternity team know enough about you to give you and your baby the best care?** [Single select]
   - Yes
   - I'm not sure
   - No

4. **Please tell us more about this** [Text entry]

5. **Did you talk to somebody in the NHS about what was important to you during your pregnancy and how you like to be supported?** [Single select]
   - Yes
   - I'm not sure
   - No

6. **Please tell us more about this** [Text entry]

7. **Did NHS staff listen to you and support you in a way that worked well for you?** [Single select]
   - No
   - Sometimes
   - Yes

8. **Please tell us more about this** [Text entry]

9. **Did the NHS give you information that was easy to understand, for example by explaining things to you or giving you information in easy read or on video?** [Single select]
   - Yes
   - Sometimes

- No

10. **Please tell us more about this** [Text entry]

8   Appendix C – Maternity Professionals Questions

1. **Please select your profession or job title.** [Single select]
   - Nurse
   - Specialist nurse
   - Midwife
   - Specialist midwife
   - Health visitor
   - Clinical support worker or healthcare assistant
   - Radiographer
   - Physiotherapist
   - Dietician
   - Other allied health professional
   - Psychologist
   - Pharmacist
   - Other scientific or therapeutic role
   - Ambulance staff
   - Non-clinical staff
   - Doula or other independent practitioner
   - Doctor – Obstetrics/ Obstetrics and Gynaecology
   - Doctor – Gynaecology
   - Doctor – Anaesthetist
   - Doctor – Physician
   - Doctor - Psychiatrist
   - Doctor – Neonatal
   - Doctor – GP
   - Doctor – Other (please specify below)
   - Other (please specify) [Text entry]

2. **If you have a particular speciality, interest or focus to your practice, please share this with us here.** [Text entry]

3. **What care setting are you usually based in?** [Single select]
   - Hospital
   - Community
   - Mental health
   - General practice
   - Other (please specify) [Text entry]

4. **Does the PRSB's Personalised Care and Support Plan Standard (summarised below) meet the diverse needs of all groups that use maternity services?**
   - **Person demographics**
   - **GP details**
   - **About me**

- **Professional contacts**
- **Personal contacts**
- **Formulation (where appropriate)**
- **Care and support plan**
- **Contingency/safety plans**
- **Additional support plans** [Single select]

  - Yes, it does
  - Don't know/unsure
  - Prefer not to say
  - No, it does not (please explain) [Text entry

5. **Feedback from our consultation so far has indicated that good personalised care and support plans are already being used. If you have a good one that you would like us to consider in our analysis, please upload a blank copy here.** [File upload]

6. **Shared decision making is an integral part of the Personalised Care and Support Plan. The PRSB's existing Shared Decision Making Standard V0.6 (summarised below) should capture the data requirements for informed decision making in maternity.**
- **Contacts with professionals**
- **Problem list**
- **Shared decision point**
- **Consent form details**

Does this standard meet the needs of recording informed decision making in maternity services? [Single select]

  - Yes, it does
  - Don't know/unsure
  - Prefer not to say
  - No, it does not (please advise what could be added to make it more suitable for use in maternity settings) [Text entry]

7. **The information detailed here and summarised below plays an important part in shaping the whole standard for maternity services, including maternal medicine.**

- **Person demographics**
- **GP practice**
- **About me**
- **Professional contacts**
- **Personal contacts**
- **Care and support plan**
- **Contingency/safety plans**
- **Additional support plans**
- **Problem list**

- **Psychosocial context (including medical health conditions and social care concerns)**
- **History**
- **Medications and medical devices**
- **Allergies and adverse reactions**
- **Safeguarding**
- **Social context**
- **Investigation results**
- **Investigations requested**
- **Referral details**

Does this information capture all the necessary details to record information about maternal medicine? [Single select]

- Yes, it does
- Don't know/unsure
- Prefer not to say
- No, it does not (please advise what changes should be made) [Text entry]

8. **The [information detailed here](#) and summarised below plays an important part in shaping the whole standard for maternity services, including fetal medicine.**

- **Person demographics**
- **GP practice**
- **About me**
- **Professional contacts**
- **Personal contacts**
- **Care and support plan**
- **Contingency/safety plans**
- **Additional support plans**
- **Problem list**
- **Psychosocial context (including medical health conditions and social care concerns)**
- **History**
- **Medications and medical devices**
- **Allergies and adverse reactions**
- **Safeguarding**
- **Social context**
- **Investigation results**
- **Investigations requested**
- **Referral details**
- **Procedures and therapies**
- **Screening**
- **Scan report**

Does this information capture all the necessary details to record information about fetal medicine? [Single select]

- Yes, it does
- Don't know/unsure
- Prefer not to say

- No, it does not (please explain) [Text entry]

9. **Does the <u>information detailed here</u> and summarised below cover all the necessary details to capture continuity of carer in maternity services?**

- **Professional contacts**
- **Contacts with professional** [Single select]

  - Yes, it does
  - Don't know/unsure
  - Prefer not to say
  - No, it does not (please explain) [Text entry]

10. **Does the following information (which matches the requirements from the national bereavement care pathway) capture all the essential details to support bereavement and loss in maternity?**
- **A flag to signal bereavement/loss**
- **Additional support plan (e.g., Bereavement care plan)**
- **Emotional and mental health assessment**
- **Referral information (e.g., to support services)**
- **Informed decision (provision of informed choices to parents)**
- **Professional contact (E.g., Bereavement lead) - includes name, role and contact details** [Single select]

  - Yes, it does
  - Don't know/unsure
  - Prefer not to say
  - No, it does not (please explain) [Text entry]

11. **Does the <u>information detailed here</u> and summarised below capture all the necessary details to record information about perinatal mental health?**
- **History**
- **Examination findings**
- **Assessments**
- **Care and support plan**
- **Contingency/safety plans**
- **Additional support plans**
- **Formulation**
- **Medication and medical devices**
- **Psychosocial context (including medical health conditions and social care concerns)**
- **Safeguarding**
- **Social context** [Single select]

  - Yes, it does
  - Don't know/unsure
  - Prefer not to say
  - No, it does not (please explain) [Text entry]

12. **Do the existing [equality and diversity information items](#) summarised below accurately capture all the characteristics and key information that could help reduce the risk of people experiencing health inequalities?**
- **Person demographics**
- **Individual requirements**
- **Social context**
- **Safeguarding**
- **About me** [Single select]

  - Yes, it does
  - Don't know/unsure
  - Prefer not to say
  - No, it does not (please explain) [Text entry]

13. **The Digital Maternity Record Standard allows a person's age and any safeguarding concerns to be recorded. Does the standard capture all the information needed to support the unique requirements of women and birthing people under the age of 18?** [Single select]
  - Yes, it does
  - Don't know/unsure
  - Prefer not to say
  - No, it does not (please explain) [Text entry]

14. **Which of the following data elements would be beneficial to include in the standard when capturing monitoring data for perinatal pelvic floor health?**
[Multiple select]
- Assessment results
- Information and advice given about pelvic health
- Compliance with information and advice given about pelvic health
- Urinary/faecal incontinence
- Urgency of bowel/bladder use
- Tear/episiotomy sustained during previous or current birth
- Forceps used in previous birth
- Current pregnancy birth details
- Exercise programme prescribed
- Referral details
- History of prolapse
- Pelvic/vaginal pain
- History of obstetric anal sphincter injury (OASI)
- I don't know/unsure
- Other (please specify) [Text entry]

15. **Thank you for making the time to take part in our survey. If you have any further comments about the Digital Maternity Record Standard information model, please share them below.** [Text entry]

9   Appendix D – Maternity System Suppliers Questions

1. **Which system supplier organisation do you work for or represent?** [Text entry]

2. **What would be useful for NHS England or the PRSB to provide to assist you in implementing the Digital Maternity Record Standard (DMRS)?** [Multiple select]
   - Use cases
   - Examples
   - Implementation toolkit
   - Release notes (including new implementation requirements for DMRS Release 2)
   - Standardisation of front-end workflow assessments/scores/questionnaires
   - Technical specifications (FHIR)
   - Examples of populated FHIR messages
   - Entity relationship diagram
   - Integration between the DMRS and Maternity Services Dataset
   - Don't know
   - Other (please specify) [Text entry]

3. **The DMRS should be used with several other PRSB standards, including the Personalised Care and Support Plan Standard, the Informed Decision Making Standard and the About Me Standard to support the new models of maternity care. What changes do you need to make in you system to implement the following? This information will be used to inform us of realistic time frames needed for system suppliers to implement the DMRS Release 2.** [Matrix/Rating Scale]

	No changes	Minor changes	Major changes	Don't know
Personalised care and support plan	○	○	○	○
Informed decision making	○	○	○	○
About me	○	○	○	○
Problem list	○	○	○	○
Smoking record	○	○	○	○
Formulation	○	○	○	○
Future appointment	○	○	○	○
Clinical narrative	○	○	○	○
Professional contacts	○	○	○	○
Labour and birth	○	○	○	○

4. **Does your system have a patient/person portal that allows people to access their record?** [Single select]
   - We have a patient/person portal
   - We are developing a patient/person portal
   - We do not have a patient/person portal, but we have future plans to develop one
   - We do not have a patient/person portal, and have no plans to develop one
   - I don't know/unsure/prefer not to say

5. **Please select all that apply to your system's patient/person portal:** [Multiple select]

- Our patient/person portal has/will have the capability to integrate with other health apps
- Our patient/person portal has/will have the capability to allow users to login with their NHS login
- Our patient/person portal has/will have the capability to allow users to input their own notes
- Our patient/person portal has/will have the capability to push information and advice to the person (e.g., information leaflets)
- Our patient/person portal has/will have the capability to display at least part of the person's maternity record to them
- None of these
- I don't know/unsure/prefer not to say
- Other relevant capability (please specify) [Text entry]

6. **What areas of the person's maternity record are visible to them through your system? (E.g., scan reports, blood results etc.)** [Text entry]

7. **Thank you for making time to take part in our survey. If you have any further comments about the Digital Maternity Record Standard information model, please share them below.** [Text entry]