Maternity record standard project – survey 2 findings

This report presents a summary of the findings from an online survey consultation conducted as part of the maternity record standard project. The survey ran from 01 March 2018 until 19 March 2018. The purpose of the consultation was to capture the views of pregnant individuals and parents, carers, healthcare professionals, and clinical information system suppliers on draft national standards for the structure and content of a maternity record standard. The draft standards consulted on via the survey were developed following an evidence review and informed by a consultation workshop held at the Royal College of Physicians on 14 December 2017 and specialist meetings on safeguarding, smoking and alcohol, and mental health and wellbeing held on 15 and 16 January 2018.

Methods

An online survey using Survey Monkey software was developed to seek feedback on draft national standards for the structure and content of a maternity record. A stakeholder mapping exercise was undertaken and the survey was communicated via a number of channels using social media, direct emails and newsletters.

The survey asked for feedback on five main areas, identified during the evidence gathering and consultation workshop phase as needing wider consultation.

These areas are:

1. Smoking of tobacco and alcohol intake
2. Mental health and well-being
3. Safeguarding and social risk factors
4. Delivery and birth record
5. Immunisations

A copy of the survey can be found

Maternity_survey2_vFINAL.pdf

Participants were given the opportunity to provide feedback on the whole draft record structure under an 'any other comments' section at the end of the survey.

Quantitative analysis of the survey responses was conducted to identify the preferred position of the survey respondents. In addition, a thematic analysis was conducted on the qualitative responses to identify common themes in the data. The findings can be found below. The following considerations were taken into account when the project team reviewed the findings:

a) a significant majority of respondents demonstrate a preference for a position;
b) a stronger rationale for an alternative minority position is demonstrated, eg patient safety;
c) a suggestion is not assessed as practical to implement at this time.

Findings

Participation Seven hundred and sixty-one people participated in the survey. A breakdown by respondent role is presented below.

Role	***No.***	***%***
Pregnant person or parent	250	29.4
Allied health professional	20	2.4
General practitioner	10	1.2
Health visitor	25	2.9
Health/care system vendor or developer	10	1.2
Informatician	25	2.9
Midwife	336	39.6
NHS administration/ management	46	5.4
Nurse	35	4.1
Obstetrician	38	4.5
Pharmacist	0	0.0
Secondary care doctor (not obstetrician)	42	4.9
Other	12	1.4
Total	**849***	**100**

* some respondents chose to enter two roles, eg informatician and clinician

Respondents were asked to provide their speciality or discipline where Patient/carer and healthcare professional respondents had experience of at least one of the following specialties or service areas:

Acute medicine
Anaesthesia
Obstetric anaesthetist
Antenatal care
General practice
Dietetics
Domestic abuse
Gynaecology
Home birth specialist
Infectious diseases
Information systems
Midwifery
Neonatal medicine
Nursing
Obstetrics
Occupational therapy
Oncology
Paediatrics
Paramedic
Patient safety
Perinatal mental health
Physiotherapy
Pregnant persons and parent representation
Provision to pregnant migrants
Psychiatry
Psychology/therapy
Public health and policy
Radiographer
Research
Risk and governance
Social work
Safeguarding
Screening

The rest of this document presents the findings from the survey, question by question. The numbers correspond to the question numbers in the survey.

3. It is proposed that alcohol intake of the pregnant woman at different stages of the pregnancy is recorded. Do you agree with the following?

	Yes		No		I am not sure		Total
Alcohol intake prior to pregnancy should be recorded (this would capture normal drinking behaviour)	85.55%	521	8.05%	49	6.40%	39	609
Alcohol intake during the first few weeks of pregnancy should be recorded (to capture alcohol intake that could pose a risk to the fetus after birth)	84.89%	517	6.40%	39	8.70%	53	609
Current alcohol intake should be recorded	90.98%	555	3.44%	21	5.57%	34	610

A thematic analysis of the qualitative responses found that respondents identify a strong evidence base for asking for current alcohol intake. While some respondents report an evidence base for recording alcohol intake during the first few weeks of pregnancy there is concern that the question could cause concern anxiety or guilt among pregnant women who continue normal drinking patterns when they are not aware that they are pregnant, and that this should be considered when collecting this information.

4. Do you think it important to record actual number of days per week of:

	Yes		No		I am not sure		Total
Alcohol consumption	76.71%	461	10.65%	64	12.65%	76	601
Binge drinking	82.91%	495	6.03%	36	11.06%	66	597

A thematic analysis of the qualitative responses revealed that respondents are generally positive about recording number of days. However they expressed the need to understand what constitutes binge drinking and to be aware that the term 'binge drinking' can be seen as judgemental by pregnant women.

5. We recommend the following options for recording frequency of alcohol consumption or frequency of binge drinking:· Never· Monthly or less· 2 to 4 times a month· If more than once weekly, record the number of days per week

	Yes		No		I am not sure		Total
Frequency of consumption	84.25%	508	6.47%	39	9.29%	56	603
Frequency of binge drinking	81.86%	492	8.49%	51	9.65%	58	601

6. Smoking status is recorded using the following options: never smoked, ex-smoker, current smoker. Do you agree with this proposal?

Agree	94.21%	553
Disagree	3.58%	21
I am not sure	2.21%	13

A thematic analysis of the qualitative data revealed that a small minority of respondents would like a record of smoking at conception. Perhaps this would be derived from other data, eg date of stopped smoking and LMP.

7. Date of stopping smoking (this can be used to calculate the length of time stopped smoking and whether smoked during current pregnancy). Do you agree with this proposal?

Agree	90.27%	529

Disagree	3.58%	21
I am not sure	6.14%	36

A thematic analysis of the qualitative data revealed that respondents thought that this information can be used to calculate if the pregnant woman stopped smoking because of pregnancy, which may be useful in identifying whether the woman would benefit from nicotine replacement products. It is recommended that the standard allows for recording of estimated date, as some women may not recall the actual date.

8. It is proposed that the use of traditional nicotine replacement therapies during the pregnancy are recorded in the maternity record (eg nicotine patches, nicotine gum, tablets, oral strips, lozenges, nasal and mouth spray), but not the type. Information recorded would be:- does not use traditional nicotine replacement products- occasionally uses traditional nicotine replacement products- regularly uses traditional nicotine replacement product. Do you agree with this proposal?

Agree	82.08%	481
Disagree	7.68%	45
I am not sure	10.24%	60

A thematic analysis of the qualitative data revealed that there needs to be a common understanding of the terms occasionally uses and regularly uses. Others reported that it would be useful to know if they use either a single product or dual products (both long and short acting NRT) as this speaks to effectiveness of therapy. Some thought that the type of NRP would be useful for research purposes. Those who do not agree that this information needs to be collected question its clinical relevance.

9. It is proposed that the use of electronic nicotine replacement products during the pregnancy are recorded in the maternity record (eg e-cigarette and nicotine vapouriser), but not the type. Information recorded would be:- does not use electronic nicotine replacement products- occasionally uses electronic nicotine replacement products- regularly uses electronic nicotine replacement product. Do you agree with this proposal?

Agree	83.70%	488
Disagree	7.20%	42
I am not sure	9.09%	53

A thematic analysis of the qualitative data revealed themes identical to those outlined in question 8 above.

10. Do you have any other comments about tobacco use in relation to the maternity record?

The themes to emerge from this question are:
- there is a need to be aware of the impact of collecting all this information on the pregnant woman, eg will she feel 'hounded'
- only information that results in a change in care to the pregnant woman should be recorded
- need to record CO levels
- need to record smoking in household

11. Should safeguarding concerns/vulnerabilities be recorded in a maternity record in a structured coded format?

Agree	81.92%	426
Disagree	4.81%	25

I am not sure	13.27%	69

A thematic analysis of the qualitative data revealed those who are positive about coding report that if will allow for recording of information in a consistent manner, information sharing among professionals and the use of data for research purposes. Those who are unsure report that there are varying degrees of vulnerabilities and concerns and question how these variations can be captured using codes. They also report that it depends on the code set and feel that text as well as codes should be available. The need for appropriate handling of this confidential data and appropriate sharing with pregnant women was a significant theme in the feedback.

12. The Emergency Care Data Set has defined a set of codes that can be used when recording safeguarding concerns/vulnerabilities in a emergency care setting. Please review the list in its entirety and make a judgement as to whether the list is suitable for use in maternity records.

Agree	62.09%	321
Disagree	13.93%	72
I am not sure	23.98%	124

A thematic analysis of the qualitative data revealed divided opinions on the suitability of the list.

> *As long as standardised across nhs & all employees are aware of the list & what each means, I don't foresee a problem.*
>
> *All options above are reasonable to ascertain levels of vulnerability and assess measures needed to safeguard and protect vulnerable individuals*
>
> *However I am not sure about the 'suspected' elements- as need to be clear what this is founded on. Similarly how do you define 'frequent' attender this could cause confusion.*
>
> *Many of these are not relevant for pregnant women. If the list is a generic one for all medical use then it's understandable, and separate codes for maternity could be cause for confusion, but if this is specifically for maternity then I don't see the relevance of some items e.g. at risk of radicalisation. Also 'family is cause for concern' is worryingly open-ended and subjective, and useless unless it must be followed up with specific comments.*
>
> *Too many overlapping categories.*
>
> *Should not become a tick box exercise, this should really inform the clinical assessment , some of these areas are complex and addressing them or even asking [about] them without adequate training could result in unintended consequences*
>
> *Many of the[se are] suspected categories - should this be formerly coded onto medical records based on one agency's assessment without other supporting evidence.*
>
> *The risk posted should be clearly defined.*

---

13. What items under question 12 (the ECDS list), if any, do not belong in a maternity record?

A thematic analysis of the qualitative data shows that the items identified most often as not belonging in a maternity record are:
6 At risk of discriminatory abuse
10 At risk of financial abuse
14 At risk of institutional abuse
17 At risk of radicalisation
20 Carer behaviour is cause for safeguarding concern
21 Child at risk
22 Child is cause for safeguarding concern
23 Delay in seeking medical advice
29 Frequent attender of accident and emergency department

14. What safeguarding concerns/vulnerabilities, if any, do not appear under the list in question 12, which you think should appear in a maternity record?

There are 'alleged', 'at risk', and 'suspected victims', but nowhere equivalent for known victims. Could it be constructed as a shorter list of slightly more broad issues, which are then qualified with 'at risk of', 'suspected victim of', 'self-declared victim of', 'known victim of' (e.g. if police/social services have confirmed)

Child abuse/ child sexual exploitation.

It does not address the most common one- concerns about parenting capacity because of impact of physical/mental illness/condition

Child or adult previously in care

Trafficked for sex work.

Learning disability.

15. What should this part of the record be called?

Safeguarding concerns	30.02%	154
Safeguarding vulnerabilities	33.92%	174
I am not sure	16.18%	83

A thematic analysis of the qualitative data revealed that the most common suggestions for alternatives names are: ‘safeguarding’, ‘safeguarding considerations’, ‘social vulnerabilities’, ‘safeguarding assessments’. Some respondents expressed the view that using the term ‘safeguarding’ in patient accessed records could put women at risk. They also noted its negative connotations and that it carries a stigma.

16. The following definition is proposed for this section of the record: A record of social factors which should be taken into account when providing care and support for the pregnant woman and the child when born. Do you think that the above description is a suitable description for use in a maternity record?

Yes	76.78%	367
I am not sure	14.02%	67
No - if so, please provide an alternative description:	9.21%	44

A thematic analysis of the qualitative data revealed that a minority of respondents thought that the definition ought to refer to the 'unborn child' (pregnancy diet, smoking, alcohol etc. can affect development in the womb) as well as the mother and when child is born.
Alternative definitions given are: 'Factors influencing social circumstances, to be included when planning and implementing care and support for mother and child', and 'A record of social factors that could pose a risk to the woman's health and well-being or that of the baby once born, which should be taken into account when providing care and support for the pregnant woman and the child when born'.

17. Should this section be called:

Social risk factors	36.80%	177
Complex social factors	25.16%	121
Complex social risk factors	10.60%	51
I am not sure	11.23%	54

A thematic analysis of the qualitative data revealed that the most popular alternativeheading suggestions is 'social factors'. Other suggestions are 'complex social and economic factors', 'social issues' and 'social considerations'.

18. Please provide examples of the 3 most common social factors that you would expect to see recorded under this heading:
The most common social factors named are:
Homelessness, asylum seeker/refugee, poverty/financial concerns, poor education, learning disability, unable to speak or read English, no family support, mental health issues. It was noted that the list could be endless and the complexity can depend on the interaction of the factors and that a definitive list should not be created.

19. In relation to the pregnant woman's CURRENT mental health and well-being, please select which of the following items you think should be recorded in: (a) a maternity record and (b) a specialist mental health record

	Maternity record		Specialist mental health record		Neither		I am not sure		Total
Current wellness (using validated assessment scale eg GAD-7 or self-report)	87.4%	369	51.9%	219	0.2%	1	4.7%	20	422
Active diagnoses	88.4%	373	71.1%	300	0.5%	2	2.8%	12	422
Current signs and symptoms	83.1%	348	67.3%	282	0.7%	3	2.9%	12	419
Current treatment, including medication	91.7%	387	70.6%	298	0.0%	0	2.6%	11	422
Current psychiatric inpatient stays	67.9%	286	82.0%	345	0.2%	1	4.0%	17	421
Suicide attempts	68.9%	290	81.2%	342	0.0%	0	5.5%	23	421
Self-harm behaviours	70.4%	295	80.7%	338	0.0%	0	5.3%	22	419
Impact of above on condition and treatment on functioning	70.6%	296	76.6%	321	0.5%	2	5.7%	24	419
Social factors that currently impact on the person’s mental health	82.7%	348	69.1%	291	0.0%	0	3.6%	15	421
Known triggers for negative impact on the person’s condition (these can be unique to that person)	78.9%	333	73.5%	310	0.0%	0	3.3%	14	422
Anxieties or fears about the current pregnancy episode	93.4%	395	60.8%	257	0.0%	0	2.6%	11	423
Key contacts within mental health services	89.8%	378	71.5%	301	0.2%	1	2.6%	11	421
Interventions, eg referral, advice and information given and actions agreed between the person and mental health professionals	81.2%	342	75.5%	318	0.2%	1	3.1%	13	421
Substance misuse	92.2%	388	69.1%	291	0.2%	1	2.4%	10	421
Family history of mental health (including perinatal mental health)	79.5%	334	66.7%	280	1.2%	5	6.0%	25	420
Negative feelings about past pregnancies, labour/birth and postnatal periods	88.8%	373	61.4%	258	0.7%	3	3.6%	15	420

20. In relation to the pregnant woman's PAST mental health and well-being, please select which of the following items you think should be recorded in: (a) a maternity record(b) a specialist mental health record*Please note you can select more than one if you think that the information should be held in two places

	Maternity record		Specialist mental health record		Neither		I am not sure		Total
Past psychiatric inpatient stays	59.52%	247	80.24%	333	0.24%	1	5.06%	21	415
Past mental health diagnoses	80.05%	333	72.36%	301	0.48%	2	4.57%	19	416
History of self-harm	66.83%	278	76.20%	317	0.72%	3	6.01%	25	416
History of suicide attempts	67.87%	281	77.05%	319	0.48%	2	4.83%	20	414
Previous referrals to mental health services	65.70%	272	77.29%	320	0.72%	3	4.35%	18	414
Past treatments	56.52%	234	78.99%	327	0.72%	3	4.11%	17	414
Success of past treatment	56.07%	231	78.40%	323	0.73%	3	5.34%	22	412
Past medication during acute episodes and medication taken over long period of time	59.90%	248	79.47%	329	0.72%	3	4.11%	17	414
Negative experiences of previous pregnancies, births/labours and postnatal periods	87.74%	365	64.42%	268	0.24%	1	3.37%	14	416

Any other comments: It depends on the definition of 'past'- is this 12 months ago, or is this 12 years ago when she was a child?
It depends how long ago these things were. If a woman self harms as a teenager then has a baby 20 years later, this should not be relevant.

22. Should the following information on birth details relating to the baby be recorded in the maternity record?

	Yes		No		I am not sure		Total
Skin to skin contact with mother in the first hour of life	80.99%	345	10.09%	43	8.92%	38	426
Rhesus status	92.71%	394	1.65%	7	5.65%	24	425
Congenital abnormalities	95.27%	403	0.71%	3	4.02%	17	423

A thematic analysis of the qualitative data revealed that respondents wanted there to be clarity about why skin to skin is being recorded and what conclusions are being drawn from it. If judgements will be made about the mother because skin to skin did not happen then the reason it did not happen needs to be recorded. Also, skin to skin may happen with the father and not the mother; it should be possible to record this.

23. Are there any items in this list which you think should be removed or any additional items which you feel are missing? If so, please provide below:

Should be removed:
3. Duration of 1st stage
5. Date and time pushing commenced
11. Pain relief indicator
14. Reason for delivery decision
29. Critical incident date
30. Critical incident type
25. Placenta disposal

Missing:
Analgesia
Pain assessment score
Membrane rupture
Mother's experience of birth
Onset of labour – spontaneous/induced, augmentation in labour
VITAL to include place of onset of care

Additional comments
Delayed cord clamping/duration
– change to reasons why cord was not allowed to stop pulsating before being cut (if any).
- amend delayed cord clamping to state optimal cord clamping as delayed has a negative connotation

24. What types of immunisations should be recorded?

	Yes		No		I am not sure		Total
Immunisations administered during pregnancy	96.69%	409	0.00%	0	3.31%	14	423
Immunisations administered prior to pregnancy	53.70%	225	22.67%	95	23.63%	99	419

Thematic analysis of qualitative date identified that respondents felt relevant that only immunisations prior to pregnancy that are relevant to pregnancy should be collected. In addition it was felt that if this information was not imported from the GP record then it would be unreliable as many pregnant women would not be able to record their previous immunisations.

25. Any other comments:

Why are examination findings restricted to this list? Why would you not record any relevant examination? Why are measurements limited to 3 items?

Concern from parents and pregnant women that personal and confidential information not relevant to their care during pregnancy is being collected.

Add dietary habits to social context.

Where can 'mongolian blue spots' be recorded?

Participation in research is missing.