I - B06. The Mandatory Detailed Analysis of every data item proposed as part of individual patient electronically-stored structured medical datasets

Comments on the kind of mandatory detailed analysis which is essential for every data item which is seriously proposed for inclusion in any Standard National (or International) Analysable Electronic Patient Record

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by

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Any Comments, Criticisms, Corrections or Suggestions for Improvement very welcome

Every data item proposed for inclusion in any Individual Care EPR needs to be analysed in terms of the following

A. Conditionality

A1. When is this Question asked

a. When will this question be asked i.e. Denominator for this question. Indicates how the computer program questions must be flow-patterned to avoid excessive data entry work by staff.
b. Frequently neglected in datasets (repeatedly in past RCOG or ENB annual statistics) is the information as to when a particular question is asked i.e. the denominator data. It is no use knowing the percentage answering ”Yes• to the question ”Did this woman have an epidural for her Labour?” if you do not know if the denominator is ”All women giving birth, including those having a planned Caesarean” or only asked of ”Those who have been in labour”. It is no use the RCOG or the ENB as in the past asking ”What percentage of women have an episiotomy?”, if Caesarean section rates vary from 10% to 40% and no-one knows if they are asking for the percentage of vaginal births who have an episiotomy or the percentage of all women having babies who have an episiotomy!
c. For this reason every question must be followed by an indication as to when this particular question is asked
d. Percentage in brackets is a rough guess as to what percentage of maternents will need to have this question answered, thus indicating the work load.
e. Style: ”Normal• Size: 10pt. Indented to 2.5 cm. for clarity

Examples

WHEN? All (100%)

or

WHEN? Only if ”Was there Labour before Birth?• = Yes (90%?)

B. The Question

B1. The Question itself

a. Using what seems, from any source, to be the best short but unambiguous question phrase in plain English.
b. This needs to be short but, if at all possible, unambiguous so that when it is downloaded into a database or spread sheet (for cross-analysis outside of it‘s original context) it still makes sense, yet leaves room for plenty of other data to be on the screen at the same time.
c. To save space a computer system will often only add the question mark when the item appears on screen, but, having originally been left out, they have now been inserted, just as an extra reminder that asking and answering a question does not happen by magic but takes time, and the time taken entering data too often detracts from direct patient care. (“Every Extra Keystroke costs!”
d. **Bold** if part of the ”Logical Priority• dataset proposals.
e. Sometimes indented to indicate when this question is only asked if a question above has had a particular answer e.g. ”Was there Labour before Birth?” is not indented. But the following question (”Type of Onset of Labour?”) is only asked if the answer was ”Yes• and is therefore indented.
f. Style ”Question” Size: 12pt.

Examples

Was there a (Previous) Failed Induction Attempt?

or

Was there Labour before Birth?

or

Type of Onset of Labour (Spontaneous or Induced/Ripening)?

B2. Confidentiality

a. All proposed data items must be considered from the point of view of confidentiality. All identification items must naturally be stripped off before the data is released for any general epidemiological analysis. For the sake of better anonymity it is also better to remove all almost all of the ”Time” items and usually the Day of the Month from all Dates. The first half of a Post Code may be retained for epidemiological purposes but the second half must similarly be stripped off before any open release.
b. The œ superscript is used for all Data Items which normally need to be deleted whenever a maternity EPR is anonymised.

Examples

Surname œ

B3. Standardisation of the Question; not the same as Coding the answer.

a. Codes such as OPCS, ICD or Read refer to the answer to such questions, not the question itself. However computer software companies such as Protos or St.Mary's SMIS always need a variable name for each question. In the case of Protos this is z code (like Read but used in a completely different way) e.g. "Baby's Surname• is .•ZMPNx•, whereas in the Mary's/SMIS system there tends to be a longer but more meaningfull variable names such as Baby_Surname.
b. For an EPR it is more important that the text of the question should be standardised rather than the answer. Rather than using some code (like Protos) or a computer variable name (like SMIS St.Mary's) in this context it is probably better to use a standardised piece of plain English but with a specific indicator to show that this phrase in question is intended to be an international standard phrase for this particular question. For this purpose it is suggested that the ® symbol should be used in superscript form just after the phrase e.g. "Was there a Labour? ® MAT"
c. See below for further comments about coding some answers.
d. A different code could be used for different specialties e.g. ®-MAT or ®-GEN or ®-ANAES

Examples

Was there Labour before Birth? ®-MAT
or

Failed Intubation? ®-ANAES

B4. Variable Names used in current maternity computer systems

Whenever available, the variable name used by the main suppliers of maternity computer system is documented

Example

Name of Baby [Euroking: Baby_name, Protos:.ZMPNz]

C. The Answer Options

See also p. for a discussion on the balance between Medical Professional and IT Professional creativity.

C1. Answer Option Selection & Wording

a. Using what seems from any source to be the best set of short but unambiguous answer phrases in plain English.
b. Great care is needed to make sure that the answers are both as simple as possible and unambiguous.
c. Answer options must be formatted in a way that, as far as possible, all reasonable options are covered, and that the selection meets the expressed needs of all interested parties e.g. If the the successor to the ENB for it's annual report continues to demand to know how many babies were delivered under the care of "Private Midwives•, then one of the options for "Responsibility for Birth Care• must be "Private Midwife•
d. The fact that a particular dataset is no longer in use does not necessarily mean that the way the questions were asked is no longer useful. There seems to be no disadvantage in including the option "Private Midwife• as someone responsible for birth care even though at present no-one asks that particular question.
e. It is as yet undecided if it is better as a matter of policy to contain some indication of the question within each answer option. e.g. "Type of Onset of Labour:• "Spontaneous• or "Spontaneous Onset of Labour•
Possible advantage: When doing later analysis on a database, then it will be easier to see which figures refer to which answer. Disadvantage: Tends to clutter up the answer options.
f. Add "(Free Text opportunity)• whenever appropriate, but try to be sparing otherwise printout summaries will become too complex. In the vast majority of cases there should not be any need for free text. e.g "Type of Onset of Labour: Spontaneous.• but "Other (Free Text opportunity)•
g. If there is a default answer this should be indicated by it's being underlined.
h. Italic. Indented to 2.5 cm. for clarity. Style: "Normal•. Size: 10pt.

Examples

Spontaneous Onset of Labour

Induction and / or Ripening (15%?)
Other (Free Text Opportunity)
Unknown

or

Yes
No

Uncertain - Possible Early Labour

C2. ”Other (Free text option)• and ”Unknown•

a. Regarding the Data Dictionary on ”The Delivery: Mode•, it has been commented by another expert that ”The separate other/unknown categories are not required•. However, in my long experience it has always turned out to be short-sighted to leave out ”Other (Free text option)• and ”Unknown• from virtually any question in any complex computer system. ”Other• and ”Unknown• may only rarely (or never) be used but it provides a simple method of highlighting problems with the way that a computer program has been written. Time and again an audit of those cases where these options have been used has provided a means to correct and improve areas where the computer system has failed to match the complexities of reality and needs further thought and development. But this need will be missed if the midwife is forced to enter an inappropriate answer due to the lack of an opportunity to answer ”Other (Free Text Opportunity)•. It is much better to allow ”Unknown• rather than have a false answer. Naturally it needs to be made clear that the coding department in each hospital should try to sort out all ”Other• or ”Unknown• answers before they release any such answers for national analysis.

b. In a numbered list it seems better to try to stick with a standard convention of using 8. for ”Other (Free text option - Please Specify)• and 9. for ”Unknown•

Examples

See below

C3. Is it an answer option or a question in disguise?

For the purposes of programming a computer and thus for this document, it is essential that all answers are mutually exclusive. In other words, using a computer database each separate question must allow a separate answer. For example, if the question is ”The persons present at birth?: with the following answer options: -Accredited specialist non consultant; -Acting obstetric registrar; -Consultant obstetrician; -Experienced obstetric SHO; -General Practitioner; -Healthcare assistant; -Medical student; -Midwife <2 years experience; -Midwife >2 years experience etc.• how can an answer be consistently given if a Midwife <2 years experience and a General Practitioner and an experienced S.H.O were all present. If that question were really important then each separate option would one by one have to be answered ”Yes / No / ?•

C4. One question or four?

Durations can only be calculated by the computer is **both the time and the date of both the start and the finish** of that episode are all entered independently e.g. The duration of Labour can only be calculated by the computer if the time and the date of both the start and the finish of labour are entered separately.

C5. Choosing the right answer (Help Button / Proposed Standard Definitions)

a. Many questions are unambiguous, but whenever there is a possibility of any confusion, then it is essential that there is a national EPR documentation as to what has been nationally agreed. It is surprising how often confusion only becomes apparent when attempting to develop a nationally agreed EPR e.g. ”Born before arrival• to doctors and hospital-based midwives generally means ”Born before arrival at the hospital• whereas I am confidently told by experienced community midwives that it has always meant ”born before the arrival of the midwife for a home birth• If a mother has had previous twins and this is her second pregnancy, one authority insists that she has had two previous pregnancies not one. It is because of such problems that it is essential for all definitions to be part of a national maternity EPR specification.

b. it is also essential that those using the computer can always be confident that pressing the help button (Normally F1) will display what has been agreed and documented nationally.

c. This section and all following sections are in 8pt print, indented to 0.2 cm to make the Question and answer stand out more clearly.

Example

HELP BUTTON / PROPOSED DEFINITION Scottish SMR02 Definition: Induction of labour indicates the type of induction used actively to start labour by clinical intervention. Some of the means used to induce labour can also be used to augment pre-existing labour that is not progressing. Induction designed to start labour must not be confused with the augmentation of labour.

or

PROPOSED DEFINITION Best if simply and clearly expressed as "1 of 1• for a singleton birth, "2 of 3• if this is the second baby to be born with the delivery of triplet

C6. Queries and Rejections

a. Many items especially numerical allow an opportunity to query or reject inappropriate answers. For example if a baby's weight is entered as more than 5 Kg it would be reasonable to ask the person entering the data to confirm the figure. If the weight is entered as 50,000 grams it should be rejected.
b. At present the level for querying and for rejecting is re-invented for every new maternity system. It will be far more efficient if such a decision is done once and nationally, and if the limits turn out to be wrong, to be corrected once and nationally.

C7. Percentages

Sometimes a percentage figure appears after an answer. This is a personal calculation to indicate how often another question follows whenever a particular answer is selected. That same percentage should then appear in the follow-on question.

Examples

See below

C8. Codes

a Many questions and answers will not have or need any code at all e.g. Was there a Labour? Yes.
b. But some answers will merit a code and in time it is intended that the correct Read or ICD or ORCS code should appear in distinctive typewriter print next to the relevant answer.

Examples

Spontaneous Onset of Labour
Induction and / or Ripening (15%?) `[OPCS: X351,  Read: .7L160]`
Other (Free Text Opportunity)
Unknown

C9. Compatibility with other Electronic Patient Records.

a. There continues to be misguided attempts to try to achieve a single comprehensive "Patient Health Record• in each hospital. Although this may be practical for simple items such as "Mothers Surname• it is unreasonable to imagine that it will be practical to have a universal pick list, for example, for all abdominal Incisions regardless of context. In a maternity computer system, for the sake of efficient and cost effective data entry the pick list cannot include all possible abdominal incisions. For practical reasons the answer options cannot be more than "1. Modified Pfannensteil•, "2. Vertical Midline•, "8. Other (Free text option)• and "9. Unknown•
b. While restricting the length of the pick list, "Other• must always be allowed and be followed by "(Free text option) • so that the letter to the GP and the information given to the woman can contain essential personal free text information on her particular unusual incision.

D. Comments Section I: Text Comments

At present this section comes straight after the answer options, but it may it time grow so large that it needs to be moved to the end of each section.

D1. Fawdry Comments

As the creator of this data resource I consider that I have to right to include, with comment, some of my own personal convictions.e.g I strongly feel that it is frightening for a woman to overhear that she has a "Third degree Tear• (akin to "Third degree burns• or "Third degree Torture•) and have therefore, with an explanation, instead used the term "Grade Three• as in many American textbooks. I am strongly persuaded that our patients will be less risk of human error when we stop using the term pH and use H ion concentration instead. At present a majority of the comments are of this nature.

Example

FAWDRY COMMENT "Missed Miscarriage• seems a much preferable term than the traditional "Missed Abortion• which is too easily misunderstood by the lay public as referring to some kind of termination of Pregnancy.

D2. Open Comments Forum (none yet)

In time it is hoped that, via the internet, the comments of many other worldwide will gradually be incorporated in the resource document at the appropriate place.

Example

None yet

D3. Referenced Comments (none yet)

a In time there will need to be cross references to the evidence for the value of each question and what is the strength of that evidence. This is especially true when data is collected which is used to assess Risk.

b. In time such references will be to actual papers or to internet sites such as that created by the West Midlands Perinatal Unit.

Example

Re: ”TB Risk, Should BCG be recommended?•

EVIDENCE & REFERENCES So far this question is only based on the MK Green Notes: ”PREVENTION OF INFANT TUBERCULOSIS. When a baby may be at special risk from TB it is recommended that, soon after birth, the baby should be given a BCG vaccination. Such a risk exists a) when one or both parents originally come from countries where tuberculosis is more common, b) where the parents belong to ”travelling• family households , or c) when tuberculosis has affected close family members at present or in the past. From the initial assessment does it seem that neonatal BCG should be recommended? No/Yes• and on the fact that the Pregnancy Notes include the phrase ”Exposure to TB. No; Yes (Details)• The evidence for such an inclusion should be References and Evidence has not yet been documented.

Re: Age of Mother at Due Date <19

EVIDENCE & REFERENCES Re: ”Perinatal Review: Teenage Pregnancy• See www.wmpi.net/reviews/tp/tp_review.htm

D4. ”Evidence-Based• Comments (none yet)

Whenever there is an ”evidence base• for any items this needs to be referenced. Work done by Ralph Settatree would seem to indicate that very few data items in a potential maternity EPR are ”evidence based• in this way.

E. Comments Section II: Getting on the best wording.

E1. Reproduction of the text used in existing Datasets

a. Only by knowing what variations already exist is it possible to identify what answer options need to be allowed and what alternative wording has been used for what seems to be the same topic.

b. Often it is found that one source has thought of answer options which have not been noticed by other sources.

c. One of the main reasons why, with so many maternity computer systems, it has been impossible to use them to provide the information required by some authorities is that the answer options have not been thought through e.g. the RCOG wanted to know how many Breeches had been delivered by Caesarean but the only relevant options in the Korner maternity dataset were: ”Vaginal Breech• or ”Caesarean• The ENB wanted to know how many women had been delivered by ”Private Midwives• but no computer currently asks that question.

d. Unfortunately there has not been sufficient time to allow any editing. This section has just be created by ”cut and pasting• what currently exists.

Example

Re: ”Type of Onset of Labour (Spontaneous or Induced/Ripening)?•

WORDING OF OTHER DATASETS KornerMat: Method of onset of labour Spontaneous; Elective C-S; Surgical (ARM); Oxytocics; Surgical & Oxytocics | RCOG Annual: Number of patients having Induction of Labour - does not include augmentation | ENB Annual: Number of Planned Inductions | Maternity Tail: Labour Onset Method | Scottish SMR02: 0 None; 1 Artificial rupture of membranes (ARM); 2 Oxytocics; 3 ARM + Oxytocics; 4 Prostaglandins (includes cervical priming); 5 ARM + prostaglandins; 6 Prostaglandins and Oxytocics; 7 Prostaglandins and ARM and Oxytocics; 8 Other; 9 Not Known. Points to Note: 1. It is important to note that induction of labour is a procedure to start labour off and is usually a planned procedure. The admission reason in these cases will probably be Code 22 (pregnant but not in labour). 2. Code 0 should be used when any of these procedure are used to assist or augment labour. Do not confuse induction methods with similar procedures used to assist or augment labour which has already started.| Revised Korner Maternity Proposals: Onset of Labour. 1. Spontaneous, 2. Labour following Induction or Ripening, 3. Caesarean before the onset of labour, 8. Unknown, 9. Other (e.g. Labour following a Road Accident???)

E2. ”Same• or ”Similar• Options

In time it would seem important to clarify what alternative wordings for questions or answers are unambiguously the same and which are similar but ambiguous. This will allow local flexibility as to what is the most easily understood local wording.

Example

Re ”Birth Number of this Baby•

WORDING OF OTHER DATASETS BAPM 97. Item 18. Plurality. Scope: All babies admitted to a neonatal intensive care unit. Level of Enumeration: Each separate episode of the baby on the neonatal intensive care unit before discharge home. Definition: The total number of births resultingn not available; 11 = singleton; 12 = first of twins; 22 = second of twins; 13 = first of triplets; 23 = second of triplets - etc. Guide for use: Plurality of a pregnancy is determined by the number of livebirths or by the number of fetuses that remain in utero at 20 weeks gestation and that are subsequently born separately. In multiple pregnancies if gestational age is unknown, only live births of any birthweight or gestational age, or fetuses weighing 400g or more are taken into account in determining plurality. Fetuses aborted before 20 completed weeks are excluded. Justification: Multiple pregnancy increases the risk of complications during pregnancy, labour and birth and is associated with higher risk of perinatal morbidity and mortality. Birth order is required to analyse pregnancy outcome according to birth order and identify the individual baby resulting from a multiple birth pregnancy. Timing: On Admission. Consistent with: Maternity contract minimum dataset, version 5 (item 32): ANZNNƒ. l MANNERS Neonatal: Order (of Plurality), an5, Birth Number of baby If Plurality > 1. Birth number. 1;2;3;4;5;6 l Previous Birth Notification(s): Ranking l CESDI96: Birth Order this Fetus/Baby.l Maternity Tail: Birth Order l KornerMat: Birth Number of this Baby, l NPEU: Plurality - Birth Number l New Birth Notification (NN4b): Birth Order (if multiple) In Data Dict?: Yes Field Size & Type: n1 Mandatory* Reject record if number of births is more than 1, but this field is not completed. Reject record if outside the range 1-9l Settatree: BIrth Order of this baby. l MCDP-DD-V1/2: Order of Infant - Positive Integer**s**

E3. Related Questions in paper Pregnancy Health Record‘s

a. What is printed will often not be the same as the flow-pattern of questions on a computer. For example in the paper record there is usually an items ”Fertility Problems?: No ; Yes (Free Text Comments)• whereas in the EPR there needs to be a whole series of about 8 flow-patterned questions to allow much more detail to be efficiently entered e.g. ”Fertility Problems?: No ; Yes•; If Yes, then ”Fertility Investigations?: No ; Yes•; If ”Yes, then ”Medical Fertility Treatment leading to this pregnancy?•: No ; Yes• ; If Yes, then ”Which Fertility Drug used: ” etc.
b. Is however important when framing the EPR question to be aware of what appears in the most commonly used patient held printed record.

Example

Re: ”Date of first antenatal care visit•

PAPER Pregnancy Notes. Not specified N.M.R.P. ”Date of first antenatal care visit•

F. Comments Section III: Include or Reject? (Is the workload worthwhile?)

F1. Reason for EPR Data Entry: Patient Encounter Assistance

The potential usefulness in the care of individual expectant mother, either for Risk Assessment, or for use in paper printed or electronic outputs needs to be clearly specified as this is the main factor is working out a the Workload/ Cost value category for each item.

Example

REASON FOR EPR DATA ENTRY
INDIVIDUAL CARE Letter to GP, Memo to Scan Department, Memo to Community Midwife
or
INDIVIDUAL CARE None?

F2. Whiteboards (Draft Ideas)

In Maternity Care it is suggested that different Whiteboards are needed on the following occassions

A. Any Antenatal Maternity Care Encounter During Pregnancy
B. Before any Anaesthetic given during Pregnancy
C. At the time of Admission in Labour or at any time during Labour
D. Before any Anaesthetic given during Labour & Birth
E. Post-Natal Mother
F Before any Postnatal Anaesthetic given to the Mother
G Neonate

In time documentation will be needed whenever a particular piece of information shouls be displayed as part of which Whiteboard

F3. Reason for EPR Data Entry: Datasets (Mainly for Later Analysis)

Document the use of this particular data items in particular datasets. For a full list and the meaning of these abbreviations, see list of datasets relevant to maternity.

Example

DATASETS (MAINLY FOR LATER ANALYSIS) Korner Maternity / RCOG Annual / ENB Annual / Tail / Contract / CESDI96 / Thames / Robson / Benchmarking / Standards / Revised Korner Maternity Proposals

F4. Installing a Maternity & Neonatal EPR computer systems by phases

For an analysis of the logical phases in the installation of maternity EPR computer systems see Appendix 3.

Examples

All Phases of Maternity EPR
Phase 1 of Maternity EPR
Phase 3_Haematology link

F5. Workload & Cost Calculation

See appendix for Fawdry Workload/Cost Categories. Workload/Cost categories depend on the phase. For example ”How many scans were done in pregnancy?• involved data entry work in a Phase 1 system when there is no on-line connection between the ultrasound computer system and the maternity system. (i.e. B1: Retrospective Analysis only •Below the Line•) but in a Phase 3_scans system such a count is computer generated and therefore Cost/Workload Free (A4: Downloaded from other Computer Systems •Above the Line•Cost Free)

Example

WORKLOAD & COST All Phases of Maternity EPR
A2: Cost Neutral (•Above the Line•) **”Start Standardising with the Fawdry 500•**

or

WORKLOAD & COST All Phases of Maternity EPR
B1: Retrospective Analysis only (•Below the Line•) **Bias against Maternity EPR Recommendation**
If 100% + Look Up (10 secs) + Data entry by Midwife. then U.K. Annual Extra Workload: 1,550 hours. Annual Cost: £31,000.

or

Phase 1 of Mat EPR C2: Paper Record enough - Mat EPR unjustifiable extra work (Maybe one day on a Pharmacy System) **Phase 1 Mat EPR Rejection Recommend**

F5. Maternity EPR Recommendation

So far this has only been based on my personal assessment of the workload cost category assigned to each item in a Phase 1 system.

Examples

See below

G. EPR technical information

G1. Eventual Electronic Inflow

A first attempt to document how, in a fully integrated EPR system, this particular item of data might eventually flow electronically from other electronic sources.

Examples

EVENTUAL ELECTRONIC INFLOW? [From Primary Care EPR]

or

EVENTUAL ELECTRONIC INFLOW? [From Blood transfusion EPR]

or

EVENTUAL ELECTRONIC INFLOW? [From Anaesthetic EPR]

or

EVENTUAL ELECTRONIC INFLOW? None?

G2. Use as Trigger

a. Based on fully discussed (and in time with RCOG supported?) national Expert ”Signposts• (NEVER RULES, PROTOCOLS OR GUIDELINES),will suggest that certain answers will act as triggers for an ”Action Suggestion•. (Always a suggestion to be included in any professional clinical judgement, never ever a rigid rule)

The decision on whether an action suggestion should or should not be followed must be a matter for the professional judgement of those providing maternity care on the spot at that time. For example if at booking the mothers blood test shows that she does not have Rubella Antibodies, then at the appropriate item (i.e. after the end of the pregnancy at whatever gestation), either on screen or as part of a printed document the ”Action Suggestion• will appear to suggest that she be given ”Rubella Antibody•. At the time of her discharge from hospital a computer question will appear as to whether she has or has not been given the vaccination. If ”Yes• then this will appear in the discharge letter to the GP and the transfer letter to the Community Midwife. If ”Refused• then there will be an opportunity to add, for example, the free text ”Has an absolute needle phobia) If ”Not given because - Went home immediately after the birth•, then the letter to the GP and the Community Midwife will still have the Action suggestion, and the personalised proforma printed out in the hospital to be filled out by hand when care is later transferred from the community midwife to the Health Visitor will have a item such as ” Rubella vaccination advised: Given. (Date . . . . Batch Number . . . .) or ”Refused (Comment . . . .) or ”Other (. . . . .)• allowing the appropriate answer to be circled using a pen before she is discharged from maternity care.

b. Documentation of Expert Opinion. For each potential use of expert guidance, there will need to be separate documentation in the form: a) what risk is under discussion (e.g. Preventing TB in neonates] b) full description of the logic of the proposals. e.g. the fact that expert opinion considers that the incidence of DVT can be reduced by appropriate use of heparin c) Appropriate references which support the logic (e.g. RCOG (e.g. RCOG guidelines on the prevention of DVTs at Caesareans)

Each

G3. Text Outputs (Paper and e-mail)

a. At this stage more detailed work needs to be done on how the output needs should be documented. Initially an attempt will be made to document what paper outputs would be needed, under what conditions.
b. If the local system allows it, in time what should currently be designed as a paper output may also or instead be sent as an e-mail. e.g. A Memo to the Scan Department, Discharge letter to GP

Examples

TEXT OUTPUT (Paper or e-mail?) Memo to Scan Department, Memo to Community Midwife, Birth Event Summary
or
TEXT OUTPUT (Paper or e-mail?) If ”Previous Caesareans• = >0 then [Special Features Sticky]

G4. Eventual Electronic Outflows?

When appropriate, in addition to the specific text messages (e.g. Memos) or letters (e.g. Discharge Letters) there will be a need for S.IN.B.A.D.S. (Standard INter program Bundles of Associated Data) to be send as a standard set of related electronic data items being sent at a particular time e.g. All the relevant maternity ante-natal and birth data being sent to a Neonatal Care System when a baby is admitted for Special Care, or all relevant data summarising a whole pregnancy to a Primary Care EPR at the end of a completed birth episode. This section will indicate under what circumstances this item will need to be include as part of which output SINBAD to which other EPR.

Example
EVENTUAL ELECTRONIC OUTFLOW? [Maternity Discharge Sinbad to Primary Care EPR] + [Birth Event Sinbad to Neonatal Care EPR]

G5. Future EPR Visibility

a. At the time of a future admission or in a primary health centre, essential current information could be lost without selecting what should be visible. For example it would not be necessary six months after a Caesarean to know immediately what kind of sutures were used or if there was a drain, but it would be important to known that this woman had had a Caesarean and had had a tubal ligation at the same time.
b. Even if not visible in a Pregnancy Summary, if this were ever needed, all the maternity data would still be stored as part of the maternity EPR e.g. Time and Date of start of the First Stage, Name of doctor who did the Caesarean etc.

Examples
FUTURE EPR VISIBILITY? Pregnancy Summary Item (but only if Tubal Ligation performed)
or
FUTURE EPR VISIBILITY? Full Maternity EPR only
or
FUTURE EPR VISIBILITY? Full Maternity EPR only (For Past Pregnancy Event Summary, Number of Babies will be clear from other data)

G6. Change control

For those using the data resource or the proposed priority dataset for designing real maternity computer systems it will be important to know if any changes have been made in the wording of any questions, conditions or answer options, and if so when. Hence this final item.

Examples

UPDATED Release 1.1 (March 2003)

H. Rejected Items

a. It is vital to document what data items have been considered and rejected and why. If not then then the discussion about whether to include or exclude each item that has been rejected has to be repeated over and over again with each new working party.
b. Since there will eventually be so many such items it is impractical for them all to be documented in the same detail. For this reason the question itself is printed out in smaller size and the rest of the section is printed in 6 pt. i.e. readable but very small.
c. Sometimes a full analysis has already been made before the item has been rejected. More often only the source of the item and the fact that it has been rejected is documented.

Examples

Feeding Intention at Initial Pregnancy Assessment ®-MAT

WHEN? All (100%)
Breast
Formula

Unknown

REASON FOR EPR DATA ENTRY INDIVIDUAL CARE (ANTE-NATAL) General Maternity Care INDIVIDUAL CARE (BIRTH & POST-NATAL) None DATASETS (MAINLY FOR LATER ANALYSIS) Purchasers
WORKLOAD & COST All Phases of Maternity EPR
C2: Paper Record enough at all stages Maternity EPR Rejection Recommended?

EVENTUAL ELECTRONIC DATAFLOW? [To Primary Care EPR]
FUTURE EPR VISIBILITY? Full Maternity EPR only MOST RECENT UPDATE March 2003

or

Cocaine

SOURCE MCDP-DD-V3 See below
Phase 1 Maternity EPR B1: Retrospective Analysis only - Paper Record enough Phase 1 Mat EPR Rejection Recommended

Concluding Comment

Documenting EPR specifications:

"a full time job for IT specialists intermittently advised, when required, by experienced clinicians•

or

"a full time job for experienced clinicians intermittently advised, when required, by IT specialists.•

There is a common view, not often openly expressed but deeply felt, that medicine is for doctors/midwives/nurses and IT is for IT professionals. So why has a consultant obstetrician spent 31 years as a consuming "hobby" and nine months on a Half pay/suspension/sabbatical working so hard to create "Fawdry's Electronic Encyclopaedia of Perinatal Data"

In fact, once a few basic principles are understood - concerning the selecting, flow-patterning, analysis and documentation of a series of questions (as set out in the Introduction to the data resource document) in a way that can be used by the those who market commercially viable EPR computer systems - , almost all the decisions made in the creation of a data resource document are those that can only be made by an experienced doctor or midwife. The place of the IT specialist would be to create an appropriate universal EPR specification design with a hypertext front end, to allow what has been created in

The document as it now exists, a) could not have been created by any IT professional (neither could it have been created by an inexperienced doctor or midwife) b) and I personally do not believe that it could even have been created by an IT professional under the guidance of an experienced doctor or midwife. c) it would have either been impossible, or have taken at least five times as long to create using a database rather than a wordprocessor approach from the start.

In summary, the whole of the data resource, encyclopaedia document has been created by me personally, and almost every decision I made could not have been made by an IT specialist.

I would suggest that the reason for this is that the most difficult part of the process are all medical professional decisions a) as to what is the optimal wording for each phrase and b) how long pick lists should be and when it is appropriate to insert "(Free text option)"

A good example of the latter sort of problem is the selection of the most appropriate way to answer the question "What was the indication for the Induction of Labour?• in a way which both adequately communicates the full information to other professionals and also meets the need of managers to have useful data.

The Maternity Care Data Project suggested the following options: -Abnormal blood flow studies; -Abnormal CTG; -Abnormal/unstable lie; -Ante-partum haemorrhage; -Breech presentation; -Diabetes; -Essential hypertension; -Fetal abnormality; -Intrauterine death; -Intrauterine growth retardation; -Intrauterine infection; -Macrosomia; -Maternal request; -Multiple pregnancy; -Oligohydramnios; -Other - fetal reason; -Other - maternal reason; -Polyhydramnios; -Poor obstetric history; -Post maturity; -Pre labour rupture of membranes; -Pregnancy induced hypertension; -Reduced fetal movements; -Rhesus disease; -Social reason.

But this is both too long for a reasonable pick list on a computer screen, yet fails to allow any free text.

My first attempt with the Protos system allowed only the following: Post Dates; Intra Uterine Growth Retardation; Pregnancy Induced Hypertension; Intra-Uterine Death; Fetal Abnormality; Other (Free text allowed). In our unit, in one year, 100 inductions required the use of the free text option. Checking through the free text options it proved impossible to reduce the actual number of different indication to less than 50 in order to communicate adequately (See Appendix 3 - when I can find out where I have stored the list on my computer!)   This led to a final recommendation, as now included in the encyclopaedia of perinatal data, as follows:

WHEN Only if "
Postdates
Pre-Eclampsia (PET)
Suspected Intra Uterine Growth Retardation (IUGR)
Spontaneous Rupture of the Membranes (SROM)
Past Obstetric History (Free Text Opportunity)
Other Obstetric Problems (Free Text Opportunity)
Maternal Pain (As reason for Induction e.g. Back Pain, Symphysis Pain etc) (Free Text)
Maternal Distress / Social Reasons (Free Text Opportunity)
Other (Free Text Opportunity)

All the decisions made in this evolutionary process could only be made by an experienced clinician with an understanding of how computers work. None of it requires an IT specialist.

(See full article on selecting answer options in EEPDPCFILES\01_ESSAYS\C_DATASETS\C£_INPUTS\Induce.pdf)

Appendix I.
Fawdry Workload/Cost Categories

ABOVE THE LINE (•Patient Encounter Assistance•)
"START STANDARDISATION WITH THE FAWDRY 500•
A1:
A1: Downloaded from PAS. (•Above the Line•) Cost Free
A1: Downloaded from PAS, or Cost Neutral (•Above the Line•) Cost Free
A1: Downloaded from PAS, or Impractical (•Above the Line•) Cost Free
A1: Downloaded from PAS / Retrospective only (•Above the Line?•) Cost Free
A2:
A2: Cost Neutral (•Above the Line•)
A2: Cost Neutral, or Individual care quality? (•Above the Line?•)
A3:
A3: Individual Care Quality (•Above the Line•)
A4:
A4: Downloaded from other Computer Systems (•Above the Line•) Cost Free
A5:
A5: Computer-Generated: based on A1-4 data (•Above the Line•) Cost Free
A5: Computer-Generated (•Above the Line•) Cost Free
A5: Computer-Generated, or Impractical (•Above the Line•)
++
BELOW THE LINE (•Paralysis by Analysis• or "Bureaucracy and Red Tape•)
BIAS AGAINST RECOMMENDATION (AT LEAST FOR PHASE 1)
B1:
B1: Retrospective Analysis only (•Below the Line•)
B2:
B2: Managerial Needs / Forecasting (•Below the Line•)
B3:
B3: Computer-Generated - but based on B1-2 data (•Below the Line•)
++
NOT RECOMMENDED (AT LEAST FOR PHASE 1)
C1:
C1: Separate E.P.R. data entry neither cost effective nor necessary
C2:
C2: Paper Record enough - At all stages
C2: Paper Record enough - Too late for EPR at this stage
C2: Paper Record enough - EPR entry impractical at this stage
C2: Paper Record enough - Maternity EPR entry probably never justified. (PAS EPR maybe)
C2: Paper Record enough - EPR entry unjustifiable extra work
++
D1:
D1: Not for Paper or EPR - Data unlikely to be available on Paper Record
D1: Not for Paper or EPR - unless computer generated
D1: Not for Paper or EPR - probably unethical to collect
D2:
D2: Not on National Paper Record - EPR entry probably impractical at this stage
++
E1:
E1: Not for Maternity or EPR - Hospital PAS enough
E2:
E2: Not for Maternity or PAS - Other EPR enough
++

Appendix 2.
Maternity EPR Installation by Phases & Modules

Phase 1 (All Hospital Scans, Labour Ward & Post-Natal, Neonatal Care)

Minimal Cost Effective Maternity Computer System. An adequate number of reliable networked Terminals and Printers a) at the Dating Scan Site, b) in the Delivery Suite, c) in each Post-Natal Ward. d) Special Care Baby Unit or equivalent. Probably at least two VDUs at each site. Electronic Links with hospital [PAS]

Phase 2 by Modules (Extra Terminals &/or Data Entry)

Data entered by hand - NOT ELECTRONICALLY. May require extra terminals and printers.

PAPER PROFORMAS ± SOME ADDITIONAL TERMINALS?
Phase 2-End_Pregnancy. End to Pregnancy not a Registrable Birth. EPAU & Gynae Ward Terminals?

Phase 2-Final_Postnatal. Some selected extra Post-natal Data regarding Baby & Mother. Community Midwives office?

BOOKING PATHOLOGY RESULTS ENTERED BY HAND
Phase 2-Booking_Blood_Results
Phase 2-Blood_Transfusion_Service_Results
Phase 2-Serum_Screening_Results
Phase 2-Haematology_Results
Phase 2-Chempathology_Results
Phase 2-Microbiology_Results

EXTRA TERMINALS
Phase 2-Pregnancy_Scans. All pregnancy related scan results entered directly onto Maternity/Pregnancy Ultrasound Computer system
Phase 2-Epau, Phase 2-Latepreg, Phase 2-GynWard etc. Early Pregnancy / Gynaecology / Day Attenders / Maternity Admissions
Phase 2-MatScans. Pregnancy related Scans results entered directly onto Maternity Computer system
Phase 2-Caesar, Phase 2-Theatre. Immediate Data Entry regarding Caesarean Sections & other pregnancy related Surgery

Phase 3 by Modules (More Electronic Links)

*Gradual Development of Electronic Links involving standardised national S.IN.B.A.D.s.**
Also relevant to the function of a possible future massive single database for each patient. Phase 3 items will help to indicate which set of data items may need to be selected for which purpose.

ELECTRONIC DATA TRANSFER FROM (AND TO?) PATHOLOGY, PHARMACY & IMAGING SUPPORT SYSTEMS

Phase 3-[Blood_Transfusion], **Phase 3-[Haematology], Phase 3-[Chempathology], Phase 3-[Microbiology], Phase 3-[Cytology], Phase 3-[Pharmacy], Phase 3-[Imaging].**

ELECTRONIC DATA TRANSFER FROM (AND TO?) OTHER COMPUTER SYSTEMS

Phase 3-[Patient_Health_Record] Electronic data transferred to and from centralised Patient_Health_Record databases
Phase 3-[Primary_Care] Electronic data transferred to and from GP/Primary Care Systems
Phase 3-[Diabetes] Electronic data transferred to and from Hospital or District Diabetic Systems
Phase 3-[AandE] Electronic data transferred from Accident and Emergency Systems
Phase 3-[Health Care Workers] Electronic data transferred from Hospital Staff Personnel Department Systems
Phase 3-[Theatre] Electronic data transferred to and from Hospital Theatre Systems
Phase 3-[Anaesthetics] Electronic data transferred to and from Hospital Anaesthetic Systems

Phase 4 by Modules (Eventual Paperless System?)

Much more expensive and less practical. Many more terminals and printers required. May never be practical.

Phase 4-Initial_Full. Terminals for the on-line direct entry of data wherever Initial Assessments take place
Phase 4-ANClinics. Terminals for the on-line direct entry of data wherever ante-natal care takes place.
Phase 4-Labour_Rooms Terminal in each Delivery Room with on-line direct entry.
Phase 4-Ward_Bedsides Terminal by each bed in the Gynaecology and the Maternity Wards with on-line direct entry.
Phase 4-Final_Postnatal Terminals for the direct entry of data in the community wherever post-natal care takes place.

*** S.IN.B.A.D**.s = **S**tandard **IN**ter-program **B**undles of **A**ssociated **D**ata