

# I - C01. Essential Characteristics required for all Computer-literate Perinatal Dataset Proposals

The Maternity Dataset Development Project is yet another secondary dataset initiative.  
No longer reasonably entitled "Minimum" or "Core".

**Datasets which are not "Credible" only add to the present confusion.**

*Based on what I have slowly learnt during my 30 years of experience of perinatal data, and especially a) on my collection of over 80 perinatal datasets, most now re-edited chronologically to allow comparisons, almost all of them for secondary usage (available under separate cover) and b) my role in providing the knowledge engineering" (clinical know-how) which led to the Protos computer system becoming the most successful U.K. maternity computer system. (About 40 out of 200 maternity units)*

*These principles may appear to be simple, but, as can be seen the attached "Assessment Table", they have repeatedly been ignored by almost all past NHS-IT dominated initiatives. (green)*

*In the light of these quite simple principles, can I suggest that you use the attached "Checklist" sheet to assess proposals for any new perinatally related datasets. (yellow)*

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

## **A. Crucially Separate Datasets!**

### **A1. "Once Only" quite separate from "Generic" Items!**

Any proposed (electronic) "Once only for each pregnancy" data items e.g. "*Was there a Labour?*", "*Date of First (Formal/Initial) Assessment*" must, for obvious reasons, be listed quite separately from recurrent (generic) items e.g. "*Blood Pressure*" or "*Biparietal Diameter*" or "*Fundal Height*" or (although of course the "*Scan Gestation used for the calculation of a Final Due Date*" - will have taken account of one specific Scan - and is therefore a "Once only for each pregnancy" item)

### **A2. "Generic Maternity" or "Generic Neonatal" separate from "Generic General Medical"!**

Generic Items which are relevant only to Maternity Care or to Neonatal Care e.g. "*Fundal Height*" or "*Babies Weight*" need to be listed quite separately from General Medical Generic Items e.g. "*Antibiotics given*",

### **A3. Mother & Baby Items quite separate!**

Mother items ("Once for every pregnancy") must always be set out quite separately from baby items (i.e. "Items which may differ for each baby in a multiple birth") e.g. "*Was there a Labour?*" should be in one set of sections and "*Time of Birth?*" or "*Apgar at 5 minutes*" which will be repeated for any multiple birth should naturally be in a quite separate sections. This division is more difficult than might at first appear but is crucial for any draft electronic record dataset proposals. Dataset proposals, such as the Korner maternity dataset, which ask staff to enter a confusing mixture of these two types of data both add unnecessary to the workload and also increase the probability of human error.

### **A4. "Every Neonate" and "Special Care Baby" Items quite separate!**

This is a recurring problem, most notably seen in the BAPM dataset and the draft MANNERS Special Care Data Set. They both include a confusing mixture of items which will inevitably need to be recorded electronically for every birth; with other items which only need to be recorded for babies admitted to special care e.g. "*Time of Birth*" should be in the "every baby" list of data items, whereas "*Reason for Admission to the Unit*" needs only to be in the dataset for Special Care Babies.

### **A5. Anaesthetic Department Items separate!**

Not essential yet, but less future problems if we get it right sooner rather than later.

Simple Labour Pain Control data items e.g. "*Use of TENS machine*" or "*Some Labour in Water used for Pain Control*" (if there is any point in recording them at all, which I doubt) should be listed separately from items such as "Epidural Anaesthesia Given" which involve the Anaesthetic department.

The former type of item, (if eventually deemed to be essential in an electronic record) will always have to be entered by the maternity department staff. In time, the later will need to be entered onto an anaesthetic departmental computer system with automatic electronic transfer to the maternity system.

## **Sub-Conclusion**

The following distinctive datasets (i.e. with no overlap) need to be clearly identified

- a) **Generic Medical** Items e.g. *Blood Pressure, Antibiotics*
- b) **Generic Maternity** Items e.g. *Fundal Height, Baby's Weight.*
- c) Every **Mother** Items e.g. *Final Due Date*
- e) Every **Neonate** Items e.g. *Birth Weight*
- f) Every baby needing additional "**Special Care**" e.g. *Cranial Ultrasound*
- g) Every item of maternal Care which involves an **Anaesthetist** e.g. *Difficult Intubation*

**There must not be any overlap between these datasets.**

## **B. Computers are not Magic Paper!**

### **B1. Separate Items - Separate!**

On paper it is acceptable to have single item which is in fact includes a whole set of questions. **This is not how computers work.** For example the Maternity Care Data Project had a single "Item (question?)" entitled "*Persons Present?*" (not just the one person "doing" the delivery) with the following list of what was, for some obscure reason called "Category Values":

*"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 / None / Other / Other non specialist doctor / Paramedic / SHO (> year 1) / SHO (Year 1) / SpR 1/2 / SpR 3/4/5 / Staff grade obstetrician / Student midwife / Student nurse."*

Although this was set out in the documentation as if it was just one question (e.g. *the previous item was "Person Supervising"*) this item is clearly not a single question at all but rather a set of 20 separate questions. And a computer needs, in some way, to store the information as to whether there was a "Yes" or a "No" or a "Don't know" answer to every one of the 20 items.

Although such questions may be presented on the screen to look like a paper document which allows only the relevant answers to be ticked, **within the computer for future analysis each answer is separate and it must be possible to analyse each potential answer separately!**

This may seem obvious but still needs to be clearly documented if only to understand the true number of questions in any dataset; and avoid giving the label "Core" or "Minimum" to dataset proposals which are clearly neither!

## B2. Hidden Multiple Questions

There also always needs to be an awareness of questions which may seem like single questions but actually require staff to take the time to enter more than that one data item. e.g. For the computer to work out "Duration of the Second Stage" it requires the following six data questions: "1. Was there a Labour?", if a Labour "2. Was there a Second Stage?", if so what was the "3. Date" & "4. Time" of "Start of Second Stage", and finally what was the "5. Date" and "6. Time" of "Birth"

**Labelling such questions "Derivative" is inadequate unless the detailed basis for any such derivative items is not also set out in full. Otherwise again there is a deception as to the true number of data items which it is proposed for an electronic record.**

## B3. Untangling of several particularly Complex Items!

In creating the Protos system several items were found to be far more complex than first expected. If the dataset is to meet the needs of all secondary stakeholders, this is especially important with regard to the following: a) "The Intended Place of Birth", b) "The Actual Place of Birth", c) "The Method of Birth", and all items related to d) Pain Control and Anaesthesia and e) the Past Obstetric History (A separate discussion document is available concerning the complex process of documenting what all the different secondary users currently require; and how the current confusion may best be sorted out.)

Sorting out such complexity still takes time; and a willingness to learn from past mistakes.

## B4. Beware of Hidden Complexity!

On paper confused questions can still be answered. Not so on a computer. For a computer system to be useful separate concepts must be kept separate.

This may seem obvious but, for example the new 2002 "Abortion Notification" Dataset contains the following question "Marital Status: Single (no Partner), Single (with Partner), Married, Widowed, Divorced, Separated, Not Known." thus confusing a question on "Civil Status" with a quite different question on "Support" (which might even be a Female Partner). With the above options it is impossible to enter consistent answers when a Divorced or Separated woman is pregnant by a supportive long term Partner. If this information is important it needs to be a separate question. If it is not important why include "Single (no Partner)", "Single (with Partner)" as two different answers. Indeed a computer database may well need separate places to store each of the following: "Partner" (who could be female)", "Husband" (from who she may be separated, "Father of the Child" (who may be considered necessary for genetic purposes)" and "Next of Kin" (if unmarried)

**Long term learning from past mistakes like this is essential if we are to avoid repeating such confusions over and over again.**

## C. Learning from Past Experience

### C1. Stop Ignoring the Lessons from Past Attempts

A recurring problem with all previous maternity database attempts by each new set of IT experts has been that such experts, in my repeated experience, **always insist on starting with a clean sheet, convinced, despite all evidence to the contrary, that this time they, the new set of IT experts, will get it right this time and that their predecessors were inadequate in their IT training.**

**This highlights the domination of NHS-IT thinking by mistaken pre-conceptions. Each time, in my experience there has been a conviction by those trained in IT that, like banking or airline ticketing, all that is needed to create a viable medical IT system is short term advice from the right set of clinical experts!!! Such experts only need to spend a few days of their time on an advisory group and all the really hard work will be done by IT people. (Incidentally part of the recurrent problem is that many clinicians have such a strong belief in the "magic" of computing that they also delude themselves in the same way!! Too many clinicians truly believe that when it comes to creating a clinical computing system all the real work will be done by IT people with only occasional advice from clinicians!!)**

Nothing could be further from the truth.

Such a simplistic approach does not work (and will never work). Fortunately my collection of past "Standard/Core/Minimum/Recommended/Obligatory" Datasets related to maternity and neonates (see EEPD Volume III) now includes in electronic form the full outcomes from the following:

"Korner Maternity/Neonatal/Obstetric Anaesthesia Datasets Initiative (1985)"

and the

"MUMMIES Project (1988-1992)"

and the

"BAPM Dataset Initiative (1997)"

and the

"Health Outcome Indicators. Normal Pregnancy and Childbirth Initiative (1997-8)"

and the

"Scottish Coppish Maternity - SMR02 and Neonatal - SMR 11 (1999-current) Initiative" Minor revisions since

and the

"Maternity Care Data Project (1998-2001)" See [www.nhsia.uk/mcd/pages](http://www.nhsia.uk/mcd/pages)

and the

"National Benchmarking Company Dataset (1998-99)"

and the

"RCOG/Settatree Initiative (2000)"

and the

"ASQUAM Project (2000)"

and the

“NOAD - Obstetric Anaesthetists Initiative (2000)”

and the

“North and South Thames Maternity and Child Health Project (2000)”

and the

“New Birth Notification and Baby Number Initiative (2001)”

and the

“MANNERS projects (2002-current)”

and several very large databases e.g. Cardiff & Oxford, etc.

and several different incompatible Congenital Anomaly Datasets

etc, etc. (Over 80 relevant datasets so far identified and mostly documented)

Copies of any (or all) of these **seriously incompatible datasets** are openly available, **in paper or electronic format**, nearly always **in their original version, but also re-organised chronologically**, to all members of our new “Maternity Dataset Development” liaison group; so we have no excuse for not doing better this time!

## C2. Chronologically and Logically arranged!

**It may have taken me hundreds of hours but this is the only reliable way to compare one draft (or existing) maternal dataset with another.**

Separate Main Sections must be chronologically arranged on the basis of the likely availability of data e.g. “Section 1. Demographic Data” followed by “Section 2. Start of Maternity Electronic Record” Data” followed by “Section 3. Initial Assessment (Booking) Data”.

And within each Main Section there must be clearly separate logical sub-sections as required e.g. *Within Initial Assessment*”, there needs to be a separate section for “Partner” items which need to be quite separate from “Family History” items which again needs to be quite separate from “Social History” items or “Past Medical History” items.

## C3. No Domination by Top Down Data Modelling techniques.

**Data modelling has an important place, especially in relatively simple computer systems but allowing this sort of top down approach to dominate automatically distorts urgent priority needs of those providing front line maternity care.**

It thus provides a sure recipe for anger and despair even from computer aware clinicians. Words such as “Data Element”, “Attribute” etc. have no place in any document presented to clinicians for quality assessment. **If they matter at all (which I doubt) they can be added after the clinicians have done their quality assessment. and never before that.**

## C4. Relation to other Data sets

Surprisingly few items in a maternity or neonatal dataset overlap with other NHS datasets. But despite the above comment, where there really is an overlap, it naturally does seem silly to promote a data item which is incompatible with other generic NHS data items (unless, as is too often

the case, the quality of the other entity is clearly sub-standard). This is especially so regarding “Health Care Staff” datasets and “Anaesthetic” data items. .

## C5. Word Processed not Spreadsheet Documents

In time, of course, all analysable data will need to be entered onto a database of some sort. **But the almost universal mistake of IT personal involved in the interface with front line clinicians is to insist on the use of a database approach at far too early a stage. In the process of creating and quality assessing any potential perinatal dataset the flexibility of cutting and pasting easily is essential.** Failure in this regard has always lead to too great a rigidity at too early a stage; and makes it far too difficult to add comments.

It also makes it much more difficult for me to re-arrange proposed data items in a chronological order for quality assessment, hence the delay in my attempting to provide any detailed comments on the current version.

## C6. Avoid Documenting of the (b\*\*\*\*y) Obvious!

If IT experts want to engage with busy clinicians they must avoid cluttering up any draft datasets with statements of the obvious e.g. Item “Diagnosis (Post Natal Depression)” does not really need the comment “Used to monitor the incidence of Post-Natal Depression”!

**Draft Dataset proposals in spreadsheet format automatically become far too large and far too cluttered with statements fo the obvious for the average front line clinician to be bothered to quality assess any output.** Incidentally the Maternity Care Data Project was far worse! It even included the Oxford dictionary definition of “Language”

This problem seems mainly to arise because of the previous mistake. Circulating a spreadsheet or database documents seems to be a certain way of ensuring that clinicians become drowned in statements of the obvious. The result, in the past, has always been that busy clinicians who have been asked to provide quality assessment get so demoralised that they feel that they have better uses for their time and give up before they can be persuaded even to start to contribute!

This has happened over and over again.

## C7. Avoid Documenting the Obviously Wrong!

Even worse is the fact that things which don't need explanation in the first place have an unnecessary explanation which is wrong! e.g. “Feeding Started Date (Breast feeding)” is not “Used to compare outcomes for babies who are breast fed”

## C8. Or Obviously Redundant!

How is it possible for two major maternity dataset initiatives to have, as separate items “Time of Birth” and “Time of Start of Third Stage”, without clearly stating that this is exactly the same as the “Time of Birth (of the last baby in multiple births)”

It is clearly because clinicians have been so disillusioned by the efforts of NHS-IT experts as to have lost interest in giving any feed back; or have been so overwhelmed by irrelevant paper as not to have noticed!

## D. Further Lessons Slowly Learnt

### D1. Documented Flow Patterning Essential!

It too often assumed that flow patterning is unnecessary for secondary data purposes. This is not so. For example if the needs of all those who need adequate information about the "Method of Birth" are taken into account, a single question is either too simplified to meet the need, or has too many alternative answer options to be practical on a computer screen. This was most notably a problem with Korner's "Method of Birth" list of options, Because it is too short hospitals were unable to use their Korner compatible computer systems to allow the reporting to the RCOG "How many breeches were delivered by Caesarean Section?".

But a full list is too long for reliable computer entry. It was for this reason that I proposed the two preparatory questions a) "*Presentation just before Birth*" and b) "*Route of Birth*" This allowed the computer to select a reasonably short list of options for each birth while also allowing the full set of 20 different methods of birth. Any set of options less than 20 fails to meet the needs of all secondary users. But simple answer option lists which are too long increase the risk of human error.

Flow patterning is also the only way to be clear as to what is being used in each case as the denominator. Only if the flow patterning is clearly set out in the dataset will it be possible to be sure that the episiotomy rate is per vaginal birth rather than leaving confusion as to whether any particular report concerns "*Episiotomy Rates per Birth (including caesareans)*" or "*Episiotomy rates per vaginal birth*".

The lack of flow patterning is one of the main reasons that the Scottish Coppins Documentation has so many pages of complex tables to identify incompatibilities such as Caesarean and Home Delivery

### D2. Best Sequence of Questions

One of the main disadvantages of electronic records is the time it takes to enter data. This is true not only for primary data sets but also regarding data entered for secondary use. Both for this reason and to reduce the risk of human error it is important to take time and get feedback as to the ideal sequence of questions. For example. Regarding Perineal Damage, this only needs to be asked if there has not been a Planned or First Stage Emergency Caesarean. Then the first question should be "*Was there an Episiotomy?*" then "*Any (further) Perineal Damage?*" to allow accurate information regarding an Episiotomy which has extended to a Grade 4 Tear, then "*Any other or further Birth Canal or Labial Damage?*" or regarding Breast feeding the best sequence to avoid confusion and to minimise human error is "*Feeding Methods at Discharge?*" followed by "*Breast Problems?*" followed by "*Other Postnatal Problems at discharge?*"

### D3. Unexpected Complexity

Some questions may at first seem to have a universally standard set of answer options.

And, in many cases it has taken me quite a long time to realise the accepted standard answer options are incomplete e.g. the standard answers to the questions

"*Outcome of Birth?*" needs to allow the additional option of "*Termination of Pregnancy*" if one is to avoid having to ask a separate question about this possibility for every delivery after 20 weeks. And the standard options for the type of Caesarean needs to include not only the list of four standard RCOG options (*Planned/Scheduled/Urgent/Crash*) but also "*Post Maternal Death Caesarean?*"

It may be argued that such detail is unnecessary for a secondary dataset but there is no good reason not to include such options when they are known exist since leaving them out now will only increase the problems with the later creation of computer systems which are (as most of them already are) concerned mainly with primary data.

### D4. Past Obstetric History is of 3 distinctive types!

Questions about the Past Obstetric History need to be clearly classified as

- i) Separate Data for each past pregnancy e.g. "*Gestation at Birth?*" or
- ii) Overview Data e.g. "*Any Previous Pre-Term Labours?*" or
- iii) Numerical e.g. "*How many previous Pre-Term births?*"

### D5. Past Obstetric History separate

The one exception to the vital chronological order of data is the Past Obstetric History. This is because the dataset at the Initial Assessment is the same as the Dataset for the Summary at the end of a full pregnancy episode.

### D6. Long Term Feed back essential!

Even for secondary datasets, quality assessment can only be done when the questions are regularly used in a real time computer systems. Yet not one NHS-IT maternity initiative has to my knowledge taken any notice whatsoever of any kind of long term feedback

This is covered in more detail in a separate discussion document using the process of finding out the most useful answer options to the question on the "*Indication for Induction?*"

## E. Academic Fantasy or Commercial Reality?

### E1. An improvement on existing Maternity Computer systems!

**Finally, and perhaps most important of all, while existing maternity computer systems (which are now in daily use in more than 70% of all maternity units) may be persuaded to alter their systems to fit sensible new proposals, any new draft dataset items which is of poor quality will, as has happened every time before, be ignored, rejected or even vigorously opposed by those using such existing systems.** Those in authority may wish otherwise; but that's what will happen. All our hard work will be wasted if what we produce is yet again fatally sub standard.

### E2. Working Understanding of Maternity Care!

Not surprisingly one of the main problems with all the work done by NHS-IT experts is how little they seem to understand how maternity care really works.

### E3. Realistic Understanding of Computers!

More surprising is the fact that, in my experience, one of the main problems with all the work done by NHS-IT experts is how little they seem to understand about how viable computer systems really work.

### E4. Learning from Commercial Success

We are unlikely to make much progress until those who control the NHS-IT budget become ready to listen and learn from IT people who have managed to sell commercially viable maternity and neonatal computer systems.

It seems silly that there has been virtually no attempt by NHS-IT personnel to learn from companies which have been commercially successful in the NHS-IT market. Indeed things have are so bad that since iSoft took over Protos it has failed to retain any of the Protos IT personnel whose long term relationships with clinicians was the major basis for the success of Protos. (iSoft, in my view partially as a result, has fallen into chaos; and their share price has dropped from 450p to less than 95p, but not until all the directors had sold their shares for a massive personal profit - See Private Eye 17th July 06)

### E5. No Dataset and Structure Secrecy!

Progress will only be made towards a useful secondary Maternity Dataset when datasets and data modelling stop being a commercial secret, and thus differ from company to company.

As a result of personal contacts I do have copies of the dataset used in Protos and the St.Mary's system, but, despite the fact that it is headed "Confidential and commercially Sensitive". I was only secretly allowed to have a copy of the "Joint London & Southern Cluster Best Practice Process Design - Maternity Draft" Such confidentiality is crazy in NHS-IT.

On the other hand I was last week offered the full Euroking dataset specification by the company itself.

## F. Paper and Electronic Records

### F1. Living with a Hybrid of Paper and Electronic Records!

It is quite clear to anyone who has practical experience of both paper records and electronic records that Paper and Electronic data items are complementary, not identical. Yet, over and over again I have been told by NHS-IT staff that, in the data modelling process, there is no need to take any account whatsoever of the difference! How blinkered.

### F2. Documenting the Uncollectable!

One of most bizarre result of a repeated failure by NHS-IT personnel to recognise the continuing importance of paper; and the fact that, for many years to come, Paper and Electronic data items are complementary, and not identical is the documentation of so many items which it would be impractical to collect universally, at least for many years ahead if not for ever. e.g. a nonsense item such as "Screening Leaflet Given?" is documented as if of the same importance as "Baby's Birth Weight?!"

### F3. Failing to Document the Easily Collectable!

In the opposite way, comparing the "Logical Prioritisation"

dataset with any existing NHS-IT attempt immediately reveals many items which it would be easy to collect reliably without any extra work and to standardise electronically but which are missing from the NHS-IT proposals. e.g. "Date of First Entry of Electronic Data regarding this Pregnancy"

### F4. Failing to Document the Essential!

Worse than the above is the fact that, comparing the "Logical Prioritisation" dataset with any existing NHS-IT attempt, scores of items which have been found to be essential in any commercial maternity computer system (and are therefore part of the "Logical Prioritisation" dataset) but which are still missing from a dataset which is claims to be "Core" or "Minimum"

### F5. Standard National Pregnancy Record

Once it finally (and inevitably) becomes accepted that any Maternity Electronic Record should complementary to (and not instead of) a Paper "Pregnancy Health Record" the massive cost and complexity of writing high quality maternity computer systems needs to be fully taken into account. In time, - the sooner the better- this will lead to a single national British Paper PHR. This may too easily be as bad as that now in use in New Zealand (Priority to financial needs, secondly to data collection, individual care needs and information for choices last) or will be based on the best possible individual care orientated paper record. Such paper records will only be of adequate quality if primarily designed as paper, not as

### F6. Clearly Discussed and Agreed Criteria for Inclusion or Exclusion of Data Items!

The present destructive confusion (each committee of "experts" creating a fresh incompatible "Core" dataset) will continue as long as no-one is prepared to discuss what logical criteria need to be used to decide what data should or should not be prioritised. In my paper entitled "Living with two hybrids: and a potentially infinite workload" I have suggested such a logical criteria but my proposals need to be debated.

## Four Crucial Final Comments

### G1. Recognising Data Creep!

Every dataset initiative in which I have been involved has added new items - such that including all that every authority might like to collect would totally overwhelm to those trying to provide clinical care. I have so far not seen any document from any other source which suggests, in any practical way how this problem may be overcome.

Indeed the standard, but impractical, answer from each group of experts is that every computer system seems to be that their dataset should become the (national/ international) standard - and so kind of "computer magic" will solve all problems regarding the incompatibility required by others. It won't!!

### G2. Documenting the Rejected is essential!

Because there are so many potential data items, if we are to make steady progress, **there needs to be clear documentation of what items have been considered and rejected; and why they were rejected!**

### G3. No Premature Top Down NHS Dictatorship!

In organisations with a long history of total dictatorship from the top down (in the USA either military or dictated by medical insurance companies), both a) with regard to their traditional paper records and b) with regard to the imposition of a single official electronic record, it has in some places been possible to move quickly towards a paperless or paperlight electronic patient record.

And there are those who see our future in such a direction.

But this is unlikely to be practical in the NHS because neither of these traditions exist. a) **There is no standard paper record in the NHS as there is in much of the USA and Canada;** and b) for good or ill, there is **no tradition of military style top down dictatorship** as seen both in the American Military or in systems dominated by Medical Insurance. In the NHS we urgently need a Wikipaedia (EPPD) approach instead.

### G4. Workload aware!

How can any NHS-IT initiative cope with such chaos.

It could allow a dictatorship of top down mediocrity.

Or we can try a different approach.

It takes time to enter data. Time which might better be used for direct patient care. Some data does need to be entered for every mother and baby; but current proposals far too often assume that all data items should be entered on everyone when either a 1 in 100 or 1 in 10 sample or b) collecting all data on a particular topic 1 month every year would provide management with just as good an indication of standards but without unnecessary extra work. (This is moire fully covered in a separate paper entitled "The Future of maternity IT: Coping with two Hybrids and a potentially Infinite Workload")

### G5. Inaccessible Datasets

While working in Cardiff, despite considerable efforts, it took me over four months to get a list of the questions and allowable answer options being collected by the long established Cardiff Maternal and Neonatal Data Collection System. Those who had set up the system had retired, and no one seemed to know how far back the data was available. Once I had managed to get documentation it became immediately clear that far too much was being collected in an unusably substandard fashion; and most of the electronic data was incompatible with the concurrent Protos system, leading to a lot of extra work for the coding clerks.

In a similar way, during my year in Banbury I was unable to get a simple list of the dates and the data included in the Oxford perinatal dataset! Why?

And now, whereas I have full printed documentation about the original 1999 Scottish Coppish system, it is now so computerised that I have not yet been able to find out how it has been updated since then.

## Summary (Two Wrong Pre-Conceptions)

- A. Almost all the senior NHS-IT “experts” that I have met still seem to have the delusion that if only they could get the right group of expert clinical advisors they will finally be given the true and only correct clinical dataset.
- B. Too many senior obstetricians still believe that computers are magic and that IT experts, with only occasional advice from clinicians, ought to be able by themselves to create viable clinical electronic records.

Neither of these pre-conceptions have any basis in truth; and we will continue to repeat the same past mistakes over and over again until we learn to overcome these two fundamental pre-conceptions.

### FINAL ASSESSMENT

- I. On the basis of the above assessment, does the current draft electronic “dataset” (it’s detailed flow pattern; and the exact wording of each question, and all associated allowable answer options) show sufficient understanding of how computers in medicine really work?

YES / NO / NOT YET

- II. On the basis of the above assessment, does the current draft “dataset” (it’s detailed flow pattern; and the exact wording of each question, and all associated allowable answer options) show an adequate understanding of how community/hospital shared care really works?

YES / NO / NOT YET

## **Conclusion regarding “The Chasm” or “Berlin Wall”**

As can be seen from the attached analysis, in almost every previous attempt by personnel trained in IT to be creative in initiatives involving front line clinicians in the development of perinatal datasets, the fixed pre-suppositions on both sides have always damaged the credibility of the outcome. Hence my use of the terms “The Chasm” or the “The Berlin Wall” regarding so much of what has repeatedly happened in the past. This was the main reason for the total failure both of the £500,000 MUMMIES project and again the total failure of the more recent £500,000 “MATERNITY CARE DATA PROJECT. (Despite much pressure for their implementation both initiatives are so inadequate that both have had to be ignored by makers of commercially viable computer systems)

Despite my recent outburst, and despite the immensity of the task we have been given, I did see some positive signs of hope with regard to the current “Maternity Dataset Development Project” but only if we are given enough time and financial support for the above principles to be taken seriously.

**At least this time there were three practising clinicians on the Liaison Group!**

**At least this time there has been some attempt to set items out chronologically.**

**And I still believe we now do have another opportunity to get things right at last**

**I do hope we don't fail yet again to produce something that those who market viable maternity computer systems will, at last, be able to take seriously.**

**Still a very long way to go! Still worthwhile attempting!**

**Rupert Fawdry, FRCS (Ed), FRCOG. 31st July 2006**

# Assessment Sheet for all Perinatal Dataset Proposals

## A. Crucially Separate Datasets!

- |  |                     |
|--|---------------------|
| A1. "Once Only" quite separate from "Generic" Items!                                   | Pass / Fail / ± / ? |
| A2. "Generic Maternity" or "Generic Neonatal" separate from "Generic General Medical"! | Pass / Fail / ± / ? |
| A3. Mother & Baby Items quite separate!  | Pass / Fail / ± / ? |
| A4. "Every Neonate" and "Special Care Baby" Items quite separate!                      | Pass / Fail / ± / ? |
| A5. Anaesthetic Department Items separate!   | Pass / Fail / ± / ? |

## B. Computers are not Magic Paper!

- |   |                     |
|---|---------------------|
| B1. Separate Items - Separate!                        | Pass / Fail / ± / ? |
| B2. Hidden Multiple Questions                         | Pass / Fail / ± / ? |
| B3. Untangling of several particularly Complex Items! | Pass / Fail / ± / ? |
| B4. Beware of Hidden Complexity!                      | Pass / Fail / ± / ? |

## C. Learning from Past Experience

- |   |                     |
|---|---------------------|
| C1. Stop Ignoring the Lessons from Past Attempts        | Pass / Fail / ± / ? |
| C2. Chronologically and Logically arranged!             | Pass / Fail / ± / ? |
| C3. No Domination by Top Down Data Modelling techniques | Pass / Fail / ± / ? |
| C4. Relation to other Data sets                         | Pass / Fail / ± / ? |
| C5. Word Processed not Spreadsheet Documents            | Pass / Fail / ± / ? |
| C6. Avoid Documenting of the (bl***) Obvious!           | Pass / Fail / ± / ? |
| C7. Avoid Documenting the Obviously Wrong!              | Pass / Fail / ± / ? |
| C8. Or Obviously Redundant!                             | Pass / Fail / ± / ? |

## D. Further Lessons Slowly Learnt

- |   |                     |
|---|---------------------|
| D1. Documented Flow Patterning Essential!             | Pass / Fail / ± / ? |
| D2. Best Sequence of Questions                        | Pass / Fail / ± / ? |
| D3. Unexpected Complexity                             | Pass / Fail / ± / ? |
| D4. Past Obstetric History is of 3 distinctive types! | Pass / Fail / ± / ? |
| D5. Past Obstetric History separate                   | Pass / Fail / ± / ? |
| D6. Long Term Feed back essential!                    | Pass / Fail / ± / ? |

## E. Academic Fantasy or Commercial Reality?

- |  |                     |
|--|---------------------|
| E1. An improvement on existing Maternity Computer systems! | Pass / Fail / ± / ? |
| E2. Working Understanding of Maternity Care!               | Pass / Fail / ± / ? |
| E3. Realistic Understanding of Computers!                  | Pass / Fail / ± / ? |
| E4. Learning from Commercial Success                       | Pass / Fail / ± / ? |
| E5. No Dataset and Structure Secrecy!                      | Pass / Fail / ± / ? |

## F. Paper and Electronic Records

- |  |                     |
|--|---------------------|
| F1. Living with a Hybrid of Paper and Electronic Records!                          | Pass / Fail / ± / ? |
| F2. Documenting the Uncollectable!   | Pass / Fail / ± / ? |
| F3. Failing to Document the Easily Collectable!                                    | Pass / Fail / ± / ? |
| F4. Failing to Document the Essential!   | Pass / Fail / ± / ? |
| F5. Standard National Pregnancy Record   | Pass / Fail / ± / ? |
| F6. Clearly Discussed and Agreed Criteria for Inclusion or Exclusion of Data Items | Pass / Fail / ± / ? |

## G. Four Crucial Final Comments

- |  |                     |
|--|---------------------|
| G1. Recognising Data Creep!                            | Pass / Fail / ± / ? |
| G2. Essential Documentation of the Rejected and Why!!! | Pass / Fail / ± / ? |
| G3. No Premature Top Down NHS Dictatorship!            | Pass / Fail / ± / ? |
| G4. Workload aware!                                    | Pass / Fail / ± / ? |
| G5. Inaccessible Datasets                              | Pass / Fail / ± / ? |

## Summary

- I. On the basis of the above assessment, does the current draft electronic "dataset" (it's detailed flow pattern; and the exact wording of each question, and all associated allowable answer options) show sufficient understanding of how computers in medicine really work? YES / NO / NOT YET
- II. On the basis of the above assessment, does the current draft "dataset" (it's detailed flow pattern; and the exact wording of each question, and all associated allowable answer options) show an adequate understanding of how community/hospital shared care really works? YES / NO / NOT YET

Rupert Fawdry, FRCS (Ed), FRCOG.

31st July 2006 (Updated 29th July 2009)