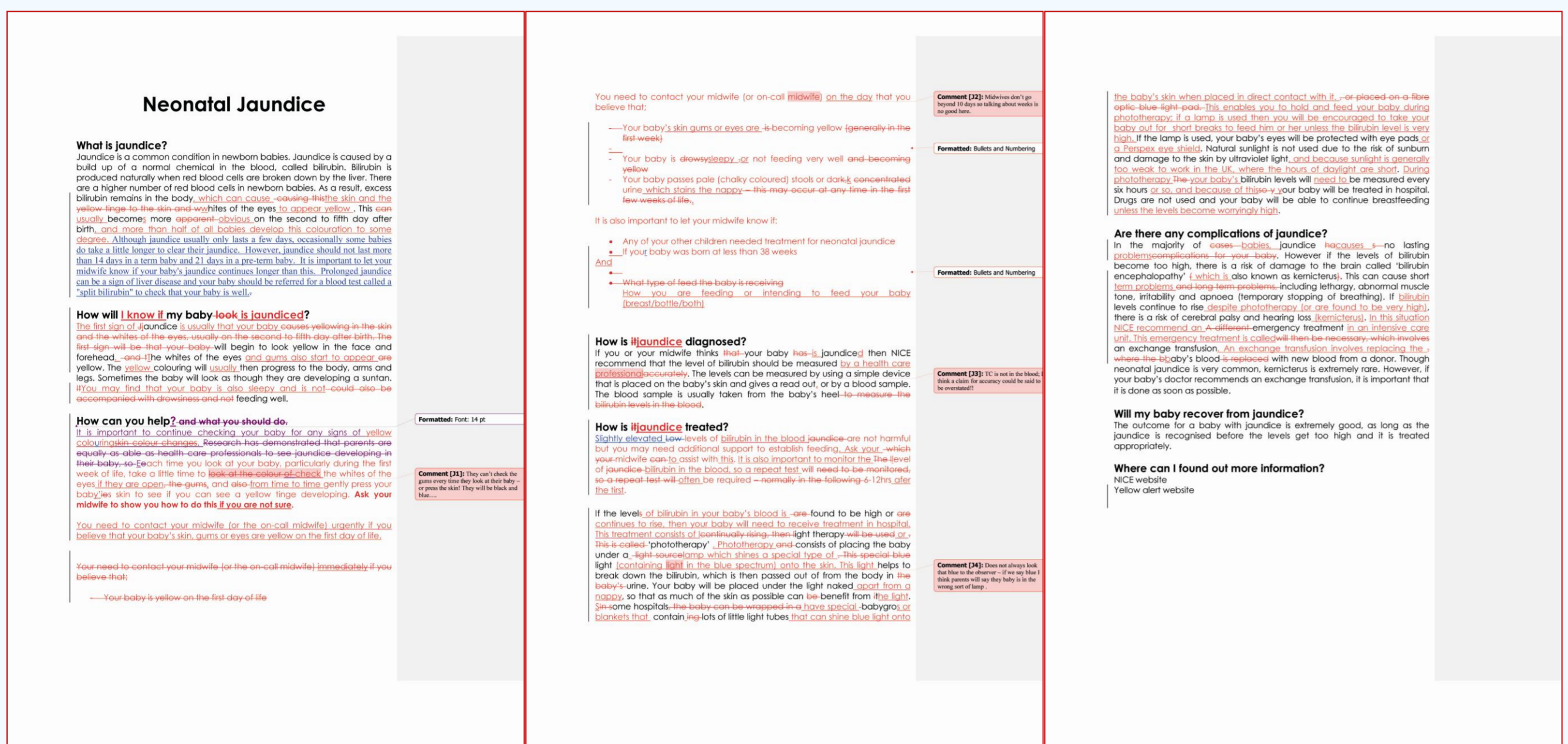


How useful is the NICE Neonatal Jaundice Parent Information Factsheet in comparison to other parent information leaflets in terms of reducing adverse outcomes of neonatal jaundice? – Key stages in its development

Juliet Kenny and Hugh McGuire, NCC-WCH, NICE implementation team and the Neonatal Jaundice GDG

STAGE 1 – INITIAL DRAFT TO ESTABLISH TEXT CONTENT FOR FACTSHEETS



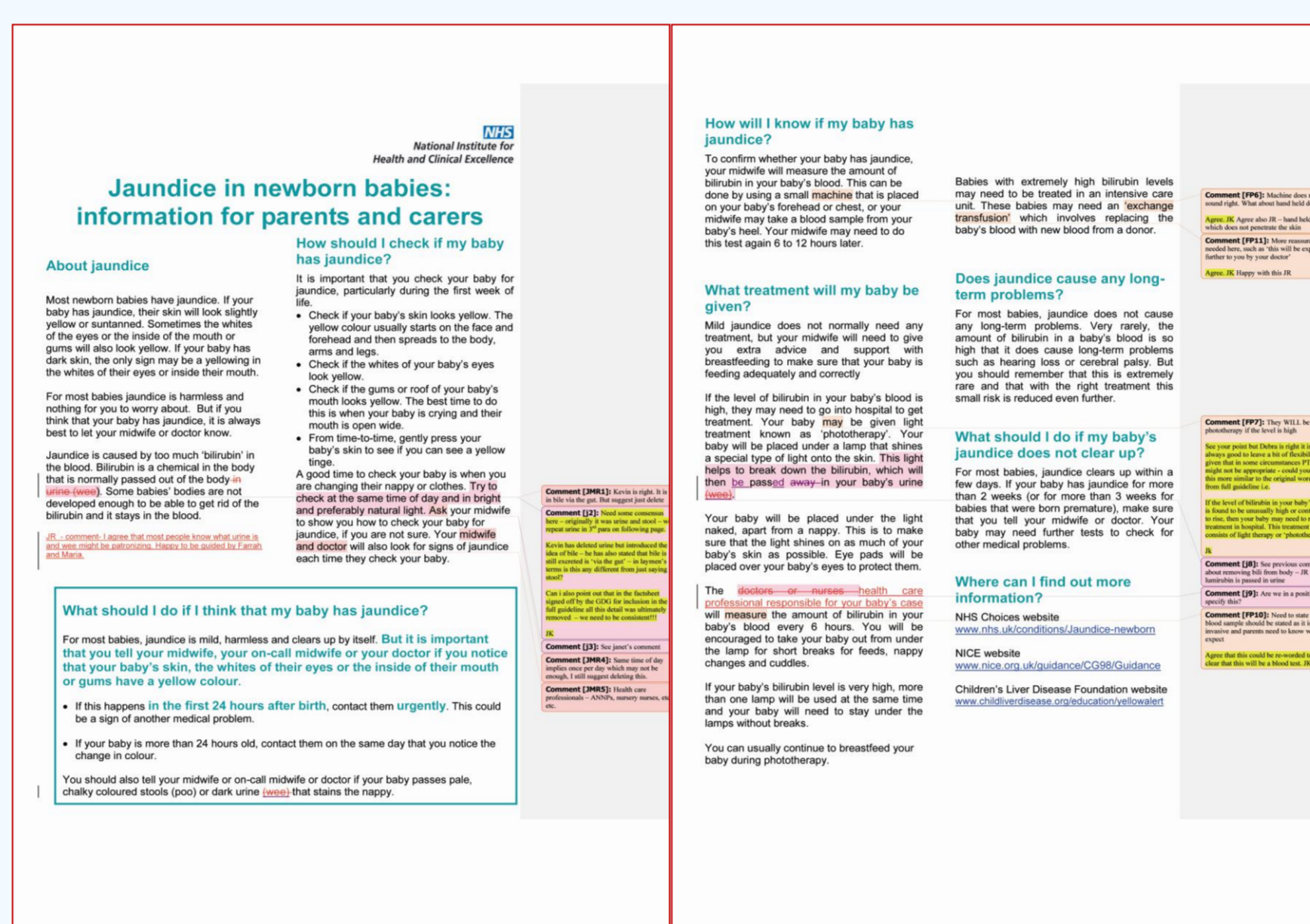
Extracts from email exchange from NCC-WCH technical team to GDG - 3/3/2010

“Low levels... - made change but used slightly instead of mildly - ok?
 High or rising... - agree that not all high bill levels require treatment but am struggling to come up with words that will express this without giving what I think would be confusing level of detail about the treatment threshold which we have not mentioned anywhere else - can you let me know what you think this should say?”
 “1) I’m not sure of the following sentence reads well.
 You need to contact your midwife (or on-call midwife) on the day that you believe that;
 - Your baby’s skin, gums or eyes are becoming yellow (generally in the first week)
 - Your baby is drowsy or not feeding very well.
 - Your baby passes pale (chalky coloured) stools or dark, concentrated urine – this may occur at any time in the first few weeks of life.
 The preceding sentence about jaundice in first 24 hours is very clear but I think this one needs a bit of tweaking to remove the repetition of ‘that’. Instructions about what to do and when is something that Denise highlighted in her email last Thursday so this needs to be watertight.
 2) Should we make some reference to multiple phototherapy? The reason being that we say that breastfeeding can continue and then jump straight to exchange transfusion... do we need to be clear to avoid parents having confused expectations about the amount of contact they can have with their baby during treatment?”

STAGE 2 – RE-WOTRCKING TO NICE LAYOUT AND RE-DRAFTING / EDITING TO 2 PAGES

Extracts from email exchange between NICE, NCC-WCH technical team and GDG - 31/3/2010

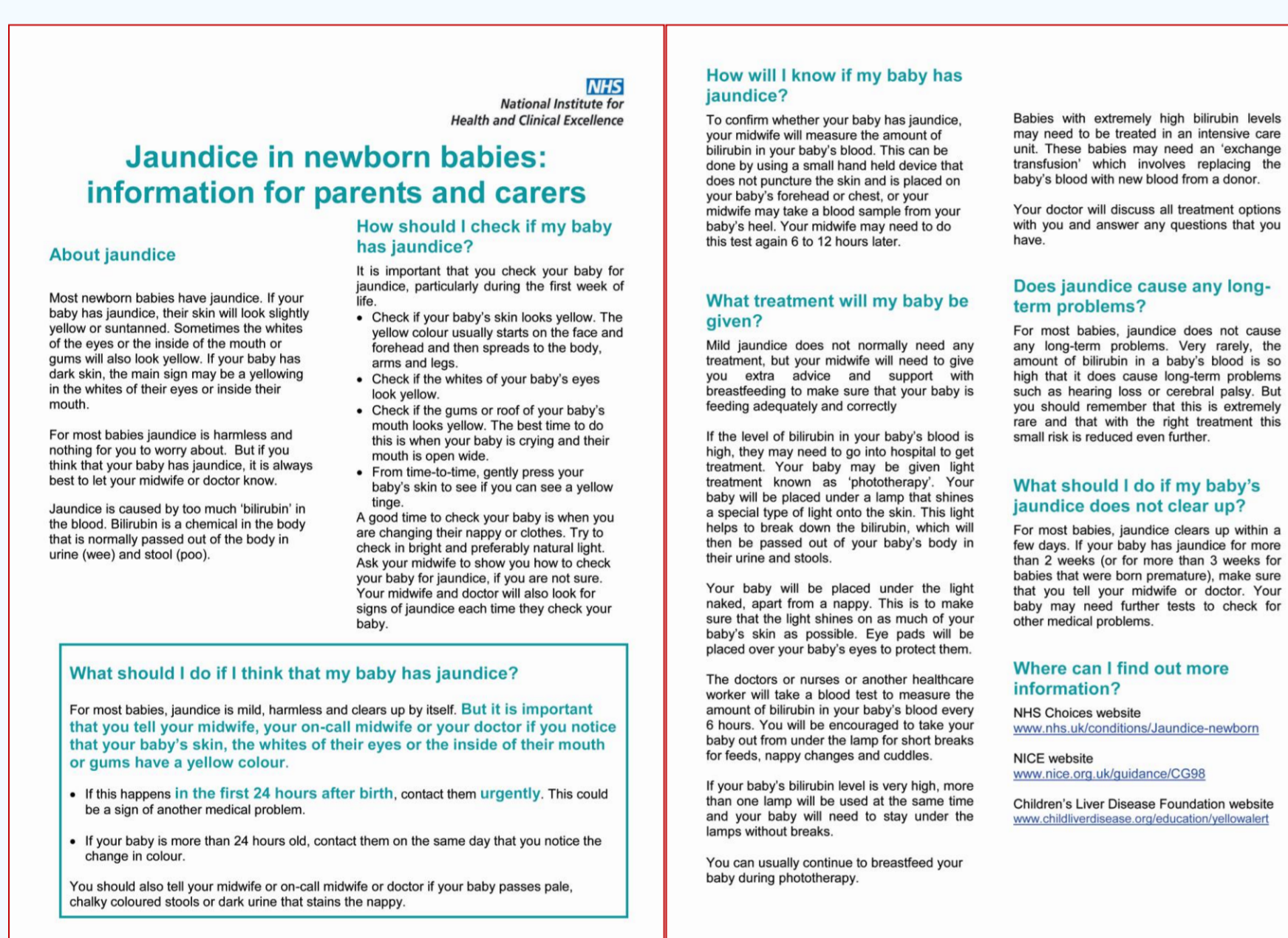
“Our main priority was to preserve as much information as possible about the visual inspection as this is the point in the pathway where we are specifically requesting parent participation.
 After this we have prioritised information about routine treatment/most likely scenarios.
 Conversely information about unusual/serious cases has been kept to a minimum.”
 “.....“we did discuss moving prolonged jaundice to the top but came to the conclusion that this does not reflect way in which we have presented the recommendations in the guideline. Equally while we have said the baby will need extra blood tests, we have not specified split-bilirubin.
 The good news is the factsheet is now:
 - only 2 pages long
 - in size 12 font
 - suitable for reading age of about 11-12 years old (similar to that of most newspapers)



SAMPLE LEALETIS COMPARED TO NINJ FACTSHEET

THEMATIC CONTENT									
THEMES	Leaflet 1	Leaflet 2	Leaflet 3	Leaflet 4	Leaflet 5	Leaflet 6	Leaflet 7	Leaflet 8	Leaflet 9
What causes it?	Adequate	Adequate	Adequate	Adequate	Adequate	Adequate	Adequate	Inadequate	Adequate
Does anything increase the risk?	Not stated	Not stated	Not stated	1 of 4 risk factors	1 of 4 risk factors	2 of 4 risk factors	1 of 4 risk factors	1 of 4 risk factors	2 of 4 risk factors
What are the signs and symptoms?	Not stated	Adequate	Not stated	Adequate	Adequate	Adequate	Adequate	Adequate	Adequate
Are there any tests or examinations needed to confirm the diagnosis?	Adequate	Adequate	Yes but not specified	Adequate	Adequate	Adequate	Adequate	Adequate	Adequate
What treatments are available? Give brief descriptions.	Stated 1 of 2 Description 0 of 2	Stated 1 of 2 Description 0 of 2	Stated 1 of 2 Description 1 of 2	Stated 1 of 2 Description 0 of 2	Stated 1 of 2 Description 1 of 2	Stated 1 of 2 Description 0 of 2	Stated 1 of 2 Description 1 of 2	Stated 2 of 2 Description 1 of 2	Stated 1 of 2 Description 1 of 2
What are the side effects and the risks of getting treatment or not getting treatment?	Adverse effects – Some Consequences – No	Adverse effects – Some Consequences – Yes	Not stated	Adverse effects – Some Consequences – No	Adverse effects – Some Consequences – No	Not stated	Adverse effects – Some Consequences – No	Adverse effects – Some Consequences – No	Adverse effects – Some Consequences – No
What are the next steps?	Adequate	Adequate	Not stated	Inadequate Blood test after 36 hours	Not stated	Inadequate - Some advice given on prolonged jaundice	Adequate	Inadequate Varies	Adequate
What can parents do?	Inadequate - Keep feeding the baby	Not stated	Not stated	Not stated	Not stated	Inadequate - Provide information about baby's health by answering the stated questions	Not stated	Not stated	Not stated
Who can they contact if they have any more questions?	Adequate	Adequate	Adequate	Adequate	Adequate	Adequate	Adequate	Adequate	Adequate

STAGE 3 – FINAL VERSION



Extracts from email exchange between NICE, NCC-WCH technical team and GDG - 6/5/2010

“You have not reached clear consensus about how bilirubin is removed from body (in stool and urine, in bile via gut etc). In the version created for inclusion in the full guideline (see email from me on 31st march attached) all this detail was removed anyway – so I suggest you remove it here too.”
 “May/Will receive treatment debate – again suggest we look to what was originally agreed in full guideline – see comment on factsheet.”
 “Colloquialisms (poo/wee) need to be used consistently.”
 “.... has commented on other communications related docs that it is not always the doctor/nurse who will do a specific procedure – service delivery is outside scope of this guideline so we need to be careful that we are not telling parents things we cannot guarantee. Again please take your lead from the version in full guideline which says ‘midwife or other healthcare professional’ – or alternatively discuss this matter with and let me know if you think this is ok to be specific in this context.”

TECHNICAL ASPECTS									
ITEM	Leaflet 1	Leaflet 2	Leaflet 3	Leaflet 4	Leaflet 5	Leaflet 6	Leaflet 7	Leaflet 8	Leaflet 9
Word count	480	569	410	552	748	883	324	492	778
Flesch Reading Ease	63.4	56.8	53.6	63.3	69.4	66.6	60.4	65.0	69.2
Flesch Kincaid Grade level	8.1	8.9	9.5	8.6	7.6	7.6	8.1	6.6	7.0
Dated	Yes	Yes	Yes	Yes	No	No	No	Yes	Yes
Review date	No	No	Yes	Yes	No	No	No	Yes	No
Author	Yes	Yes	Yes	No	No	Yes	Yes	Yes	No
Contact details	Yes	Yes	No	No	Yes	Yes	Yes	Yes	Yes
Website address	Yes	No	No	No	Yes	Yes	Yes	No	No
Leaflet code	Yes	No	No	Yes	No	Yes	Yes	No	Yes
Copyright note of organisation	No	No	No	Yes	No	No	No	No	No
Logo	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes
Font size between 12 and 14	Yes	No	No	No	Yes	No	No	No	Yes
Dark print on light	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Justify to left	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Clear headings	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes

BACKGROUND: The Parent Information Factsheet (PIF) was conceived of by the Neonatal Jaundice Guideline Development Group (GDG) following discussion that identified a specific problem in recognizing jaundice. Evidence reviewed showed that, with minimal training, parents/caretakers were often equally good at recognizing jaundice as health care professionals. The GDG were concerned that, although capable, parents/caretakers may not be empowered to check for jaundice and what to do if jaundice was recognized. The GDG set an important recommendation they had made about measuring bilirubin levels if jaundice was recognized. It was therefore important to address this knowledge gap and empower parents/caretakers to be active participants in caring for their babies. After further discussion of various ways of disseminating information based on their individual experience of different clinical/patient needs, the GDG chose to develop a PIF that was specific to their guidance to facilitate its implementation post-publication. An evaluation study was carried out to assess the PIF’s usefulness in comparison to other existing leaflets

METHODS: Existing parent information leaflets were identified by an Internet search. Each of the identified leaflets was compared to the GDG PIF and each was analyzed for readability and content. Readability was assessed using the Flesch reading score and the Flesch-Kincaid grade level. The higher the reading score, the easier a document is to read while the Flesch-Kincaid Grade level indicates the level of schooling required to read and understand a document. Content was assessed and presented as percentage congruent with the GDG leaflet. Sample emails between NCC-WCH technical team and the GDG are used to illustrate the process.

RESULTS: We examined 9 information leaflets identified by Google and Yahoo searches on 16/7/2010. Two leaflets were excluded – 1 because it dealt with neonatal wellbeing including jaundice and the other because it dealt with prolonged jaundice only. The GDG PIF compared favourable with the mean scores on number of word (939 vs 582 ± 185), Flesch Reading Ease (73.8 vs 62.6 ± 4.9) and Flesch-Kincaid Grade level (=7.2 vs 8 ± 0.9). Of the twelve items on the NHS toolkit for designing leaflets, all the leaflets met three criteria, (dark print on light, justify to left and clear headings) Criteria dealing with copyright and review date were only met by 2 and 3 leaflets respectively. No tool met all the criteria.

In terms of content, many of the items which the GDG felt were important, (recognition, what parents should do, risk factor, treatment and consequence of no treatment) were either not stated in the sample of leaflets or were inadequately presented. For example, in the category of what can parents do for themselves, one leaflet suggests ‘keep feeding the baby’ and another ‘provide information about baby’s health by answering stated questions’ These go against one of the findings of this guideline, i.e. that parents are as good as clinical staff at checking their baby for jaundice and against a key recommendation that if anybody thinks the baby is jaundiced then its bilirubin level should be assessed.

Several risk factors identified by the evidence review were not stated by these leaflets while others e.g. cephalohaematoma were listed despite these be shown not to be important by the evidence reviews. Only one leaflet presented information on the risks of not getting treatment while the remainder reported on phototherapy but not exchange transfusion.

DISCUSSION: Overall the rationale for drafting an evidence based and toolkit supported information leaflet is vindicated by the varied quality and themes in some existing leaflets. Using recommendations developed according to NICE methodology, and following the NHS toolkit for designing information leaflets, the GDG with the support of the NICE implementation team were able to produce a patient information factsheet that is freely available on the internet, of a higher standard than comparable publications, more useful across a range of clinical scenarios and promotes parent involvement in decision making.

LEARNING OBJECTIVES (TRAINING GOALS):

1. Research on a limited sample of publicly available parent information leaflets on neonatal jaundice has demonstrated that many of these are inaccurate, misleading and incomplete.
2. Support from the NICE implementation team and a leaflet checklist facilitated the GDG development of an evidence-based leaflet that makes it easier for health care professionals to support clinical guidance.
3. As parents representatives were involved in the GDG and the development of this leaflet, the GDG also helps empower parents which was one of the priority recommendations of this guideline and is a major failing of the reviewed information leaflets.

Acknowledgements:

We would like to thank the NICE Implementation team, the Neonatal Jaundice GDG and the NCC-WCH for their support and advice during the development of this information leaflet.