

5 December 2006

From Suzy Chapman & Ciaran Farrell

Consultation, consultation, consultation?

A couple of minutes into his keynote address to the 12th May Invest in ME Conference, Dr Ian Gibson, Chair of the Gibson Inquiry Group, stated:

“We will have the Minister in...and ask them what their attitude is, and she will have her officials with her, so in that sense it’s going to be a formal inquiry - there’s going to be a report. I’m absolutely determined to get that report out before we break up at the end of July. We have a debate and we hit the media airwaves with it after we’ve got consultation from groups, like your group here.”

A few minutes later, Dr Gibson said:

“...I wish I had the inquiry results in front of me now, so you could say hang on a minute - that’s nonsense or whatever...”

The Gibson Inquiry Report was published on 26th November, several months behind schedule. It was submitted to NICE at the eleventh hour, on 24th November - the final day of the NICE consultation period.

The Report was submitted to NICE without any consultation between the Gibson Inquiry Group and the ME community over the content of the Report. One possible reason for this is that the Gibson Inquiry Group simply did not complete their Report in time to enable the contents to be discussed prior to its submission to NICE. Another reason relates to the delays and inefficiencies in the production of the Report and the unwillingness on the part of the Gibson Inquiry Group to be open, honest and transparent about the Report’s contents and prospective recommendations, and an unwillingness to be open to scrutiny and to constructive criticism on these issues.

Having submitted their Report to NICE, the Report was then embargoed. It wasn’t published until two days later, by which time it was too late for the contents of the Report to be reviewed by those groups and individuals who had delayed submission of their own responses in the NICE consultation process, in the expectation that the Report would be published before the NICE consultation period closed. In fact, it wasn’t initially clear whether the Report had been finished in time to meet the NICE deadline.

On 23rd November, the day before the Gibson Group submitted their Report, NICE had issued a statement of clarification concerning the submission of responses:

“If stakeholders choose to make a submission other than through the web proforma, it will be read by the guideline developers but it will not receive a written response.”

The Gibson Group are registered stakeholders. We have been led to understand that the Group chose not to submit its Report via the web proforma. It was therefore submitted to NICE in the knowledge that NICE would receive this Report on a ‘for information purposes only’ basis, which means that NICE does not have to comment on the contents of this document or respond to the Gibson Group - NICE can ignore the contents of this document if it chooses to do so. In doing so, the Gibson Group were fully aware of the implications of their actions.

The Report was finally “launched” on Sunday, 26th November. We place the word “launched” in inverted commas since no Press Conference was held and there has been virtually no press coverage, although Dr Gibson, Chair of the Group, evidently had no trouble, last week, in securing coverage of his latest project - a call for another inquiry, this one into the possible dangers of Wi-Fi.*

“Preview” copies of the embargoed Report were strategically seeded amongst selected recipients.

Early responses, delivered under the guise of “summaries”, “highlights”, “digests” and “press releases” failed to provide either a balanced précis of the Report or a balanced evaluation of its worth and contents, or both.

It is recognised that these “previewers” had deliberately capitalised upon their VIP status with the Gibson Inquiry Group in order to spin the content and status of the Gibson Report, as well as to make claims about the Report’s prospective ability to change the fortunes of the ME community at the highest level. In doing so, they intended to steer opinion in favour of the positive aspects of the Gibson Inquiry project, by cherry picking only those issues within the Report that suited their purpose and ignoring all other aspects of the Report’s contents, the status of the Inquiry and the problematic history of the Inquiry project to date.

Another view is that these “previewers” sought to pull off a reputation-saving exercise for some of the high profile individuals associated with the process of this “inquiry”.

The “previewers” news agenda was to seize the day and by doing so, get the ME community onside, and so naturally they did not wish to relinquish it when others raised critical voices about the Report, its contents, the status of the Gibson Inquiry, or their own actions. Therefore, they briefed against the publishing of any critical analysis and denigrated those who were criticising both the Report, itself, and the way in which these “previewers” had set about presenting the Report to the ME community.

Now that other ME advocates, charity representatives and the ME patient community have had time to download a copy and to study this document, in full, balanced and considered critical analysis is emerging.

It is clear that this Report does require very careful scrutiny for considerable concerns are now being expressed for the credibility, content and implications of this document and for the way in which this entire “inquiry” has been carried out.

Do not rely solely on “summaries” and “digests” for an overview or for forming an opinion - download a copy of the full document at:

<http://www.erythos.com/gibsonenquiry/Report.html>

In an attempt to deflect attention away from areas of concern being raised by others, various excuses for the document’s ‘shortcomings’ have been proffered: lack of resources, Lord Turnberg, lack of scientifically qualified support staff. Very legitimate concerns for the content of the Report, as it stands, have been disparaged, with the implication that any perceived ‘weaknesses’ in the Report will likely be addressed by an “independent inquiry by appropriately qualified and independent experts”.

This fails to reassure, since it is by no means certain that the Group’s call for a “proper inquiry by experts” will result in any full and proper inquiry, at all. In the

meantime, the ME patient community has been presented with what many consider to be a most unsatisfactory and potentially damaging document.

What opportunities are there for the ME community to engage in consultation with the Gibson Group now that this Report has been published?

In her mailing of 29th November, Margaret Williams asserts:

“Dr Gibson’s office has confirmed that all feedback will be considered, and the Group will determine the best way forwards in the light of the feedback received.”

This unofficial statement, put out by Ms Williams, is at complete odds with the official statement issued by the Gibson Office, the previous day:

The One Click Group: Gibson Office Statement

28 November 2006 17:27

“The Gibson Inquiry is not out for consultation/amendment. The aim of the report is to reflect the opinions of the Group after spending a year receiving and reviewing evidence.”

We have therefore raised a number of questions with the Gibson Group which are appended.

- <http://comment.silicon.com/weeklyroundup/0,39024756,39164494,00.htm>

“Dr Ian Gibson MP, former chairman of the commons science and technology committee, has called on the Department of Health to invest some tax-payers’ money into finding out just how dangerous wi-fi is. Gibson says the Department of Health must set up an inquiry along the lines of the Stewart Report into mobile phone radiation.”

Questions for Dr Ian Gibson, MP, Chair, Group on Scientific Research into ME:

05 December 2006

1] On 12th May 2006, towards the beginning of his keynote address to the Invest in ME Conference, Dr Gibson expressed a clear commitment to a consultation process being held after the Report had been completed and before it was released to the media.

Would the Group please confirm if any form of consultation process was held with any of the patient groups, organisations or individuals who presented at the Oral Hearings, or with any of those who submitted written evidence or with any members of the wider ME community before the Report was released?

What form, if any, did this consultation process take, when did it take place and which patient groups and/or individuals were consulted?

2] If no consultation process was held, prior to the document’s release, what were the reasons for this decision, whose decision was this, and when was this taken?

3] Would the Group please clarify whether any form of formal or informal consultation process is currently in progress and how, and by whom, this is being managed?

If this is the case, how are any responses to be elicited via formal or informal consultation to be used a) in relation to the contents of the Report, as it stands; b) to inform the Group's decisions about how to proceed?

4] On 12th May 2006, at the Invest in ME Conference, Dr Gibson expressed his desire that the forthcoming NICE guidelines should be fit for purpose. Dr Gibson has since informed the press, via the 26 November Press Release, that "These [NICE] guidelines have been widely criticised by patient groups and by the APPG on ME. Chair Des Turner described them in a meeting last week as 'not fit for man nor beast' Dr Ian Gibson MP of the Inquiry described them as 'useless'."

Would the Group please confirm that the Gibson Report was tendered to NICE in a form other than on the web proforma and the basis on which NICE has accepted this document from them?

If it is the case that the Report has been submitted on a 'for information only' basis, what was the reason for this decision, whose decision was this, and when was it taken?

If it is the case, how does this course of action accord with Dr Gibson's stated intention at the Invest in ME Conference that the findings and recommendations of the Report should help inform the process of the development of the NICE guidelines?

5] On 12th May 2006, at the Invest in ME Conference, Dr Gibson spoke of the need to facilitate patient groups and individuals in influencing government departments.

How does this statement accord with the Group's decision to submit the Report to NICE and publish the Report "sight unseen" as it were, by the patient groups and individuals whose interests this Report represents, and with the Group's statement, on 28th November, that "The Gibson Inquiry is not out for consultation/amendment."?

6] It is understood that there are plans for the Report to be officially presented to government some time in the next couple of weeks.

Given that this inquiry has been an unofficial inquiry and given that the Gibson Group is not a Select Committee, or an APPG, or any official House of Commons/Lords official committee, what impact does the Gibson Inquiry Group consider its Report and the recommendations made within it will have on government, Department of Health and other bodies, bearing in mind that the Inquiry Group cannot rely on the formal and official channels of processes and procedures which official committees have the right to expect?

In what ways does the Group intend to use its Report to achieve implementation of its recommendations?

7] It is understood that a "meeting" or "reception" or "symposium" is to be held some time in the future to which those who gave evidence and presentations at the Oral Hearings are to be invited.

Would the Group please clarify what the purpose of this meeting/reception/symposium is?

Has a date and venue been set for this proposed meeting/reception/symposium?

Who does the Group intend to invite to this meeting/reception/symposium in addition to those who presented at the Oral Hearings?

Will this meeting/reception/symposium be held in public so that members of the public can attend and participate?

8] Would Dr Gibson consider attending a meeting specifically set up in order to discuss the content of the Report with the ME community and to discuss how the Group intends to proceed?

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