



**Dialogue:
Context, Conspiracy, Pseudonym and Self-Report Data:
discussion of 'Reporting Consciousness in Coma'**

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*A Dialogue In Response to 'Reporting consciousness in coma:
media framing of neuro-scientific research, hope,
and the response of families with relatives in vegetative and
minimally conscious states'*

Abstract

In the following dialogue Professor Lionel Naccache engages Prof Jenny Kitzinger and Dr Gabrielle Samuels in debate about their recent *JOMEC Journal* paper about news reporting of consciousness in coma patients (Kitzinger and Samuel 2013). Professor Naccache's letter appears first, followed by a response from Kitzinger and Samuel.

Contributor Notes

Professor Lionel Naccache is a neurologist and hold a PhD in cognitive neurosciences from Paris VI University. His thesis, written under the supervision of Professor Stanislas Dehaene, is entitled *The Subliminal Perception of Numbers: Psychological Properties and Functional Brain Imaging of Unconscious Cognitive Processes*. He now works both as a neurologist in the unit for nervous system diseases at Pitié-Salpêtrière in Paris, and as a professor at Paris VI University. He is co-director of the Neuropsychology and Neuroimaging unit (INSERM, the French National Institute of Health and Medical Research) within the ICM (Institut du Cerveau et de la Moëlle épinière). He has published essays on neurosciences of consciousness and subjectivity. His primary interest is the cerebral basis of consciousness.

Jenny Kitzinger is Professor of Communications Research at Cardiff University School of Journalism, Media and Cultural Studies. She is also co-director of the York-Cardiff Chronic Disorders of Consciousness Group. Jenny's work focuses on health and science issue – previous books have addressed the AIDS crisis, the history of sexual violence, and, more recently, human genetic research. She is currently researching family experiences of severe brain injury.

Gabrielle Samuel is a Wellcome Trust funded PhD student in Medical sociology at the Centre for Biomedicine and Society at Brunel University, London. Her research interests include the social and ethical issues surrounding innovative health technologies and the portrayal of science/technology in the media. Gabrielle also has an interest in biomedical ethics and is a member of the London and Brighton Translational Ethics Centre (LABTEC).

A few comments about 'Reporting consciousness in coma' by Samuel and Kitinger – Lionel Naccache

Dear Editors,

I was very interested by the recent report of Samuel and Kitinger in JOMEK journal, entitled 'Reporting consciousness in coma' (2013), dedicated to the study of how the media framing of neuro-scientific research impacts on families with relatives being in the vegetative or minimally conscious state. As being directly concerned by this issue both as a neurologist taking care of such patients and of their families, and as a researcher in this field, I would like to congratulate the authors for their original work which should stimulate similar research in social sciences, and also to react on two points. I will first begin by clarifying a misunderstanding related to a citation of an editorial I published in Science magazine in 2006.

1) What I meant by 'rich mental life' in the 2006 Science editorial?

Samuel and Kitinger analyzed the impact of a seminal functional brain-imaging case-study exploring brain activity of a patient clinically defined as being in the vegetative state. In this article published in Science in 2006, Owen and colleagues (2006) used the fMRI signal to detect two reproducible and sustained patterns of brain activity specific to two distinct mental imagery tasks: 'imagine playing tennis' and 'imagine walking through your house' respectively. Samuel and Kitinger then cited my editorial in the same issue of Science, in which I wrote that this study indicates the presence of a '*rich mental life*' (Naccache 2006), and they

interpreted my paper as source of 'potential confusion about the level of cognitive ability detected by fMRI' (Samuel and Kitinger 2013). I agree that the 'cut-and-paste' extraction of these 3 words ('rich mental life') may be confusing, but I regret the authors did not pay attention – or did not report – the general tone of my article in which I tried to expose with clarity the interest and limitations of this study, and discussed the perspectives of this new promising approach. My editorial was even entitled '*Is she conscious?*' to emphasize the questions raised by this study rather than drawing oversimplified conclusions. In this editorial I proposed a very balanced interpretation of this important study. These three words meant that, indeed, finding in this patient the very same robust and reproducible neural signature of a complex cognitive task as the one measured in conscious controls during the same task, was a strong evidence for the existence of rich cognitive abilities including in particular semantic and executive processes. One issue I discussed in this paper was the interpretation of this result as a univocal sign of conscious processing: in particular because during the last 20 years we (and many other researchers) discovered many high-level cognitive processes operating unconsciously both in controls and in many distinct neurological patients (see for instance reviews and discussions in (Dehaene and Naccache 2001; Naccache 2006; (Naccache 2008)). In other terms, I meant that there was univocal existence of rich cognitive processes in this patient, but I discussed at length the difficulty to infer with certainty that she was (or not) conscious and experienced first person perspective contents. I even proposed methodological developments to address this decisive and tough issue. My paper closed by stating explicitly that

this study was: *'not totally convincing on the issue of consciousness'*. After reading Samuel and Kitzinger paper, I consider I may have used the expression 'rich cognitive processes' rather than 'rich mental life' in order to avoid the confusion with a univocal conscious subjective content experiences by the patient in first person perspective. This is also probably what my colleagues Joseph Fins and Nicholas Schiff (2006) expressed in their own paper criticizing my expression (I discovered their paper after reading Samuel and Kitzinger' article). I only regret that Samuel and Kitzinger – who criticize with reason superficial reading of sources – only reproduced a very small 'chunk' of my editorial, while missing the general tone of the paper. Actually, I'm very concerned by these issues with the patients and families I'm taking care of, and all my public conferences, articles and books (see for instance the dedicate chapter in my essay 'Perdons-nous connaissance?' (Naccache 2010)) attest of my concern about illegitimate claims derived from these new promising tools, and about the complex and highly variable impact of these studies on families and relatives of patients. As most of my colleagues, when I examine a patient and explore his brain structure and activity, I also spend time before and after (and usually keep contact later in time) with his relatives. This relation with relatives is not only crucial, but on many occasions it is even more important than the diagnostic stage itself (see below) to help them live with such complex situations. Therefore, whereas I completely share with Samuel and Kitzinger the necessity to permanently question both the way we (as physicians and scientists) communicate to society, and the way our works are framed in media, I am left with a bitter taste of unfair treatment in their paper.

2) Respect the complexity of the subject and avoid 'plot' theories

While I found Samuel and Kitzinger contribution profound and questioning, I was left on several occasions with an impression of over-simplification. Three illustrations may clarify this impression.

First, the authors regularly refer to explicit motivations of scientists emphasizing too much their results, regardless of illegitimate hopes elicited by this form of bold communication in minds of relatives of patients: *'Such 'promises' can be made via practices in the lab, grant applications, publications, and via press releases and media statements'* (1) and *'part of a deliberate effort by scientists (and science funding bodies) to promote their work and enroll support and resources for its development'* (10). Such behaviors may exist, – of course – but I'm not certain this explanatory statement fully covers the complexity of scientific communication behaviors. I think most of these behaviors stem from implicit processes driven by the organization of science and medical systems (importance of impact-factor, or scientific and medical fame), rather than from deliberate explicit strategies of individuals ('plot theory'-like explanations). I'm sorry to refer again to my personal case, but my introspection does not reveal me to be a greedy and selfish Mr Hyde hidden deeply behind the physician and scientist I have tried to be for years now, a physician full of limitations obviously but who tries to act and to communicate honestly. Nevertheless, I fully agree on the importance to dissect these complex systemic processes which are probably at the origin of biases in the way scientists communicate to society, and in particular in such a specific field.

My second illustration is related to the obvious fact that relatives of chronic vegetative state or minimally conscious state patients have to go through complex psychological processes including denial, the mourning process, and acceptance of a new condition for their loved ones. This irrepressible chain of processes shows a large inter-individual variability. Therefore, one has to be particularly cautious when trying to find explanatory variables. In the paper, Samuel and Kitzinger fairly described subjective reactions of some relatives to fMRI and similar neuroscientific methods. However, neuropsychology taught us that while subjective reports are a rich source of information about how the individual consciously feels about himself and about the world, one does not have to take these reports at face value in terms of explanatory power. When an individual goes through a mourning process he/she will spontaneously reinterpret previous beliefs and hopes, and therefore it is highly difficult to establish causality links here: does she/he regret her/his previous beliefs in fMRI because of the way she/he was informed about these technics; or alternatively is the mourning process (or similar psychological process) explaining her/his change of mind regarding these tools irrespective of the way she/he was informed about their existence? I do not have the answer, obviously, and I don't think there is any definitive answer for a given individual. However, one should be lucid of these complex intermingling processes when dealing with the issue raised by Samuel and Kitzinger. This argument is not framed here to discourage any effort in the field by shaking the repulsing 'complexity' argument. On the contrary should I say, but lucidity is here even

more mandatory than elsewhere.

Finally, I consider that the authors should have used the same rigorous attitudes they advise with wisdom to others (e.g.: avoidance of superficial processing of sources'; lucidity of motivations behind the official discourses). As a scientist and physician used to describe patients or subjects in articles without using strategies prone to elicit empathetic feelings in readers, I was a bit surprised by the use of false names when describing patients and relatives: 'In the interests of confidentiality, all names used in this article have been changed to pseudonyms'. (1) Typically, one may use generic labels (patient #1, relative#1, or acronyms, P1). If the name of a subject is false, but is still deliberately used as a name in an article, what can be the motivation of its presence in the text except the goal of eliciting emotional identification processes in the reader? This remark is not stated as a severe critique of the paper, but rather as a call for lucidity and humility. When promoting an ethical attitude, please do not forget yourself in the process, even if in the present case this technique of name-substitution is frequent in non-scientific media.

Beyond these issues and mild criticisms, I would like to sincerely congratulate again the authors. We should definitely enrich our knowledge of the way relatives are affected by communication of scientists and physicians in order to improve our communication behaviors. I'm ready to further contribute, with them and others, to this long-standing effort.

Very cordially yours,

Prof Lionel Naccache

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**A response to Naccache's comment
on 'Reporting consciousness in coma'
– Jenny Kitzinger and Gabby Samuel**

Dear Editors,

We appreciate Lionel Naccache's positive comments on our paper (Samuel and Kitzinger 2013), and also his critical engagement with some of what we wrote (Naccache, JOMEK, this issue). We respond to the issues he raises below.

1) 'Rich mental life':

We stand by our claim that Naccache's reference to the fMRI findings as demonstrating a 'rich mental life' in seemingly unconscious, severely brain injured patients was a source of potential confusion. However, on reflection we think it would have been useful and courteous to state that Naccache's comment about a 'rich mental life' did not reflect the general tone of his editorial and to reference work in which he raises concerns about illegitimate claims and the complex impact of these studies on families. We hope that Naccache's summary of his position (JOMEK journal, this issue) will serve to clarify this issue, as well as offering a useful complement to our article in discussing some of the complex issues involved in interpreting the fMRI research.

2) Conspiracy/Plot theories:

Naccache questions our statements about the promise-making activities of scientists. As we said in our article, our research is built on and develops research on the 'sociology of expectations' and the 'political economy

of hope' (see references in our original article). This is a body of work which has explored the ways in which scientific research and development is commonly justified – e.g., by claims of imminent medical breakthroughs – and how these promises can be framed to attract sponsors or enrol a supportive policy context. Our assertion – particularly flagged up as problematic by Naccache – that 'Such 'promises' can be made via practices in the lab, grant applications, publications, and via press releases and media statements' as 'part of a deliberate effort by scientists (and science funding bodies) to promote their work and enrol support and resources for its development' was designed to do no more than set the context for our particular focus on press releases and the media. We treated these ideas as simply a jumping-off point for our own study, and in so doing we perhaps failed to convey the sophistication and complexity of their theoretical perspective which has little in common with the caricatured notions of evil scientists conspiring for power criticized by Naccache. We certainly did not intend to conjure up the Jekyll and Hyde image Naccache invokes when he seeks to rebut our claim with his observation that 'introspection does not reveal me a greedy and selfish Mr Hyde hidden deeply behind the physician and scientist I'm trying to be...', a physician full of limitations obviously but who tries to act and to communicate honestly'. Rather we are trying to understand individual actions in the context (as we said in our article) of 'the institutional and structural' forces that promote hype and we agree with Naccache that attempts to address this issue will need to look at such context. This is something we have highlighted in other work too. For example, one of us (JK) served on the Nuffield Council on

Bioethics working party on 'Novel neurotechnologies: intervening in the brain', stewarding the section on communicating science which concludes with a recommendation that:

government, higher education funding councils and universities reflect on the effects that the 'impact agenda' might be having on the ways in which the promises and limitation of novel neurotechnologies are communicated by academic institutions and their researchers. [NCoB 2013: 220]

Use of pseudonyms rather than ID numbers:

Naccache comments that 'as a scientist and physician' he is used to using 'patient #1' or 'relative#2', and expresses surprise – and some concern – about our use of pseudonyms: 'what can be the motivation [for using a pseudonym]', he asks, 'except the goal of eliciting emotional identification?' This is an important issue because this surprise and concern highlights a difference of disciplinary practice. We did not in fact consider the pros and cons of pseudonyms (in comparison with numeric identifiers) when we wrote our paper. We used them by default – a position that reflects our socialization into social sciences/humanities research traditions. But, on reflection, it is also a practice rooted in our commitment to presenting research participants empathetically – trying to understand their beliefs and perspectives, even when (perhaps especially when) they differ from our own – and help readers to engage with the stories told by participants. Rather than see the potential of pseudonyms to elicit

identification as a problem we, in common with many qualitative researchers, value such an approach (e.g. see Cassell 2005: 190). In social science text books pseudonyms are recommended in preference to letter and numerical codes, to 'give more life to interview excerpts' (Schilling 2013: 253) and to make them 'more memorable' and help 'readers navigate their way through the analysis' (Wood et al., 2009: 157). We believe we would lose something of the quality of our data if we re-worded extracts from our original article to read (for example) that 'Relative #9' said "it's not something that I could personally put Patient #6 through.... it's modern technology that has put Patient #6 where she is today". One author, JK, is working on a larger network of research into disorders of consciousness in collaboration with colleagues from across Cardiff University and the University of York (e.g., Kitzinger and Kitzinger 2013 a, b; Halliday et al 2014, Holland et al 2014) and pseudonyms are also the identification of preference for this larger body of work. Given that this more extensive study included sometimes conducting separate interviews with several members of the same family, the strategy of using numeric codes could be even more problematic for some of these data extracts which might end up something like:

I asked Relative #34 to talk to the doctor about Patient #26 and she asked Relative #35 [other sister] to come with her and [Relative #35] said 'Relative#15, why don't you talk to the doctor yourself?' And I said, because he doesn't pay attention to anything I say. (R15)

Experimenting with 'neutral' numeric identifiers confirms for us what other

commentators suggest – that personal stories ‘defy the anonymity of a number’ (Seidman 2013: 9) and that ‘pseudonyms remind us that [this] is about individuals, not cases or numbers’ (Morash 2010: 21). Research participants may also have preferences here. For example, the Health Experience Research Group at Oxford University which is custodian of almost 3000 narrative interviews with patients informing the healthtalkonline.com website originally assigned numbers to interviewees, but found that participants preferred an alias (Zeibland 2014: personal communication). The same proved true with the new research participants in the on-going research being conducted for the healthtalkonline website by Jenny Kitzinger and Celia Kitzinger: when (prompted by Naccache’s letter) interviewees were asked what they would prefer, there was a clear preference for pseudonyms. For example; one interviewee responded robustly: ‘I am a person not a number’.

4) Use of self-report data:

This leads into the final point which is the challenge of how one treats self-report data. Naccache comments that family members of patients in a vegetative state (PVS) or minimally conscious state (MCS) ‘go through complex psychological processes including denial, mourning process, and acceptance of a new condition for their beloved’ and that during this process they may ‘spontaneously reinterpret previous beliefs and hopes’. He argues that as such family members’ reports do not have to be taken at face value. This is an important point: it is well established in social science research that self-report data is subject to influences such as social desirability effects, interviewer effects, fallible memories and faulty

understandings (Miller and Glassner 2011). Indeed, we can confirm this on the basis of data from one of the author’s (JK’s) involvement in the larger on-going research study mentioned above. Different and sometimes conflicting or incompatible ‘facts’ about the patient and his or her treatment are sometimes conveyed in interviews with different members of the patient’s family. The research also shows that even the same person, interviewed on a second occasion some months or years later, can give a significantly different account of key events. One current initiative is to carry out a comparative analysis of a family member’s account of a particular experimental neuroscience interventions on her relative at two different points in time: first when the interviewee was still hopeful that the patient might recover, and then, some years later, when she no longer believed that recovery was possible. Insights from this work, as well as the wider debate about the benefits and risks of ‘transparent’, ‘discourse analytic’ or ‘psychoanalytic’ interpretations of narratives, inform our agreement with Naccache that a ‘transparent’ approach to interview data has its limitations – and we certainly consider that it prudent to explore alternatives (see Kitzinger and Wilkinson 1997).

We accept that the problems of taking retrospective data at face value make it ‘highly difficult to establish causality links’ and we are not trying to make straightforward causal claims of ‘X causes Y’. Our work on ‘consciousness in coma’ is not a ‘media effects’ study. The strongest ‘causal’ term we use is where we refer to an interviewee’s excitement about fMRI having been first ‘triggered’ by a media report. In using the word ‘triggered’ we sought to allow for the wider context of how, for example, the

interviewee's access to other information and the dynamics of hope in such a traumatic situation may contribute to any response to an individual item of news. As clinicians often indicate (and as is echoed by research participants' own reflections) what 'triggers' excitement/hope may be embedded in a much wider context. The hope invested in an experimental intervention/assessment may not be simply dependent on what is presented in any particular newspaper report or on what the scientist/clinician says to a family member when presenting the study in any particular encounter. There may also be a difference between what is stated (e.g. in a newspaper report or a consultation) and what is understood and recalled by the reader/family member. This is one reason why any publicity about novel neuroscience, or the offer of new intervention, has to be handled with such care. In order to address this Jenny Kitzinger is now involved in developing a new programme of research that, it is hoped, will include video recording consultations about treatment decisions, including, if possible, consultations about involving patients in experimental research.

In conclusion, we note that self-report data from all interviewees has its limitations (as identified above). It is important not to disqualify our interviewees' accounts in particular on the basis of the 'mourning' and 'complex psychological processes' that they have experienced as family members of a PVS/MCS patient (see Kitzinger and Kitzinger 2014). Our interviewees' accounts can not be treated at face

value nor do they transparently convey causal explanations – but we believe there is positive potential in looking to family members as a source of insight contributing to good practice in this area – whether that is as part of a jigsaw to reflect on the representation of fMRI in public discourse (Samuel and Kitzinger 2013), to try to improve experiences of long-term care (Latchem and Kitzinger 2012), or to focus on the practices and context of decision making about medical treatment (Kitzinger and Kitzinger, 2013a, b).

We would like to thank Lionel Naccache for provoking us to deeper thought about our engagement with this debate and reflection on our methods. We hope that social scientists, scientists and physicians can work together to continue efforts to improve communication – in medical/research consultations, media relations and public debate – and look forward to future collaborations and engagement.

Yours faithfully

Prof Jenny Kitzinger and Dr Gabrielle Samuel

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