

Open letter to the Dementia Alliance International

13 October 2014

I am taking this opportunity to thank you for the inspiring work that you do in the 'Dementia Alliance International' (DAI). It has fast become a powerful and influential international group leading on important global policy strands for the dementias.

I am an academic interested in the international policy approaches for living well with dementia. I may not be familiar to some of you. The recent G8 dementia event in London, and the recent subsequent legacy event, have been useful for progress in a key part of policy internationally. I think, however, it is now important that we also take stock who people feel benefited from such initiatives. I will be presenting my recent research, which I enclose, at the 24th Alzheimer Europe conference next week in Glasgow. Kate Swaffer, Secretary to the DAI, is in fact a co-author of mine on these studies as she made important contributions to the interpretation of the studies. I hope this research makes for compelling reading.

Innovation is without doubt an important strand in policy. I had the fortune to study innovation management in detail for my own MBA, although my own background had originally been in medicine and cognitive neurology at Cambridge and in London. My paper in the highly cited academic journal *Brain* from 1999 describes, with evidence, an innovative way of making an early and timely diagnosis of the behavioural variant of frontotemporal dementia. The validity of this original contribution has been supported many times by my colleagues, and furthermore is presented in the current Oxford Textbook of Medicine.

Anyone who has had training in dementia and innovation will know exactly what the complexity of the challenge presented by innovations in dementia is. I will be enormously happy to see Dr Dennis Gillings and the World Dementia Council succeed, but I am rather disappointed by the sentence presented below (*and highlighted in red*), if reported correctly here by the Telegraph newspaper from the UK.

I feel personally the statement, **without any bad intention on the part of Dr Gillings I am quite sure**, offends the ethical pillars of autonomy and dignity of people living with dementia. This coincidentally is the title of the Alzheimer Europe conference I am attending next week. The statement also poses potentially concerns within the prism of the legal notion of mental capacity.

In his first interview since being appointed by David Cameron to create a new World Dementia Council, Dr Gillings suggested that society owed it to dementia sufferers to activate for them.

He said: "I would like to see far more people with dementia being put into clinical research trials, so that once we find a drug is safe we introduce it to a wider population earlier. **With HIV the patients themselves were the activists - with dementia it is different so we need communities and families to activate on their behalf.**"

[Source: <http://www.telegraph.co.uk/health/elderhealth/10714039/Thousands-of-dementia-sufferers-should-be-offered-drug-trials.html>]

I recently wrote and published a book, 'Living well with dementia' (<http://www.radcliffehealth.com/shop/living-well-dementia-importance-person-and-environment-wellbeing>).

Its main Foreword is written by Prof John Hodges from NeuRa (and previously from Cambridge). I wished to include two chapters on innovation for dementia policy. I therefore included two detailed chapter on assistive living and ambient assisted living technologies in dementia. The critical thing I learnt from my review of the literature is that successful diffusion and adoption of innovations are essential – whether innovations spread and get taken up, in layman language.

I feel that the World Dementia Council would be making a massive strategic mistake if it did not think to include the views of persons living with dementia, at a senior level and beyond, in its decision making. Firstly, it is essential to have some representation of views on whether innovations can spread and can get taken up. Secondly, people living with dementia must be included for the moral integrity, sustainability, license to operate and reputation of the World Dementia Council. Prof Michael Porter and colleagues have helpfully articulated this framework at Harvard of what constitutes a good 'corporate citizen'. This mistake will be obvious to anyone with knowledge of the field of innovation in dementia. There is absolutely no shortage of leadership with the membership body of Dementia Alliance International.

Please do accept my apologies for writing you this short note in open. I wish for an open and transparent discussion of this policy, as it progresses.

I have every confidence in the people leading the World Dementia Council, but I think, sadly, the World Dementia Council will only have authority if it includes and engages seriously the people it purports to serve.

With best wishes.

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Queen's Scholar (1987)

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Bachelor of Law (2009) BPP Law School

Master of Law (with commendation) (2011) (in international commercial law) (University of Law of England and Wales)

Master of Business Administration (2012) (BPP Business School)

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