

**PE1463/HHHH**

Petitioner Letter of 21 September 2016

Dear Convener and Members of the Petitions Committee,

The Scottish Government commissioned Thyroid UK to conduct a survey as **part** of a Listening Exercise to establish why patients were unhappy with their thyroid treatment. I quote the then Health Minister Michael Mathieson's letter to the committee "However, we are sympathetic to the experiences of the petitioners and others who find themselves unable to obtain or access a diagnosis or a treatment they feel should be available. We will therefore commission a piece of work to explore how patients understand and feel about their quest for a diagnosis and/or treatment in areas where the evidence is limited, the science is uncertain or disputed and/or where a condition is rare or obscure, or not widely recognised. This will include a listening exercise with patients and also with staff dealing with patients with such experiences. The aim of this project is to help illuminate the concerns and perceptions of patients in such circumstances and so support efforts to improve communications and patient engagement." Clearly they failed to deliver this and the survey was the sole result of two years of 'Listening'. "We are grateful to Thyroid UK for undertaking this listening exercise. It is, however, worth reiterating that this was not a scientific survey and is thus likely to have an overrepresentation of people with adverse symptoms. It may not therefore be truly representative of all people on thyroxine...Both anecdotal and clinical observation can be useful to raise scientific questions, but in the meantime we must rely on the evidence base." This is a shocking waste of two years, a waste of tax pounds and a total disregard for the patients who expended their very limited energy on a comprehensive survey. The aim was to help 'illuminate' the concerns of patients; it was not a scientific survey to be peer reviewed in a journal. That nothing has come of it does not surprise me in the least. Perhaps the Scottish Government focus is too taken up with the legality of the Named Person legislation to bother with the health of Scottish citizens?

I won't even bother rebutting the contents of the Scottish Government's letter of 2nd August 2016. The very definition of madness is doing the same thing over and over again and expecting a different result. For four years I, along with Thyroid UK and respected doctors, have rebutted, with evidence, the Scottish Government, British Thyroid Association, Royal College of Physicians and British Thyroid Foundation. These organisations **are** the problem and they are doing everything in their power to maintain the status quo. To that end, I respectfully ask the committee to consider inviting Dr John Midgley to give evidence and throw some light on just why we are in this circular argument and getting nowhere. I am sure the committee must be as tired of this whole debacle as I am.

Lorraine Cleaver, Petitioner