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Nuclear Regulatory Commission Request for Information Concerning Patient Release Practices

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General Comment

The NRC is to be commended for deciding to solicit the views of the interested public on this important issue.

I am at a disadvantage, of course, in that I do not know the actual questions intended to be put to the public by the NRC, but only their gist. With that qualification, I think that they are properly directed, and that the time estimate for collection is probably reasonable, with the understanding that this is an aggregate figure, and that individuals may choose to respond either briefly or at length.

I realize that the objective of the data collection is to identify sources of guidance that stakeholders, including patients, consider to be valuable and worth adopting widely. It is possible, however, that it may be that there are elements of more than one source that should be drawn on, rather than just one source that is better than any other. There is also the question of whether there are approaches not currently being used that could be adapted to help inform patients. For example, there is a urologist I know of who has prepared a 45-minute video for prospective prostate cancer patients. Rather than trying to inform each patient orally, his approach is to say, Here is a video. I want you to watch this, and after you have done so, we will meet, and I can answer any further questions you have. I am not aware that this is being done with thyroid cancer patients, and I believe that it could be extremely valuable.

To get a full picture of whether guidance is fully responsive to patients needs, it would be useful to sound out the patient community on actual experience. The questions that I outline below are designed to do that. In this way, the proposed guidance can be matched to the problem areas identified by patients.

I hope that the questions elicit the details of patients individual experiences in seeking guidance. A patient may get advice from more than one source: possibly first from the licensee, then from the internet, then from a support group, etc., and finds that one is more useful than another, or that one complements another, or that one contradicts another.

It might be valuable to ask patients, as a threshold matter: (1) in what year or years were you treated; (2) how many times were you treated; (3) how many millicuries of I-131 did you receive on each occasion; (4) were you hospitalized or treated on an outpatient basis; (5) if on an outpatient basis, were you released immediately after being dosed, or asked to remain on the licensees premises for some period of time before leaving (e.g., until after first urination, or for two hours, etc.); (6) if you were asked to remain for some period of time, where were you asked to wait; (7) were you given an anti-emetic; (8) if you were given an anti-emetic, was this precautionary or after reporting symptoms of nausea; (9) did you experience nausea or vomiting, and if so, where were you at that time; (10) were you released to your own home, and if not, where to; (11) if you went to a hotel or motel, was that at the licensees direction or on your own initiative; (12) if the latter, was the licensee aware that you were going to a hotel or motel; (13) if you went to a hotel or motel, was the management aware that you had radioactivity in your system; (14) what means of transportation, if any, did you use to get to your destination; (15) were you prepared for treatment by withdrawal of thyroid medication or by the use of recombinant thyroid stimulator hormone (Thyrogen); etc. (The point of the last question is that patients who are prepared for treatment by an injection of recombinant TSH do not experience the effects of hypothyroidism, which can include mental fog and slowed reflexes, such that driving may be hazardous and instructions difficult to comprehend and follow.)

Only then might the following be asked: (1) what guidance if any did you get from the provider; (2) was it in written form, oral form, or both; (3) was it volunteered or did you have to ask for it; (4) was it sufficient to meet your needs; (5) did you obtain additional information elsewhere, and if so where, and what was it; (6) did what you learned elsewhere agree with what the provider told you; (7) where do you feel that you got the most useful and valid information; (8) in retrospect, did you feel that you received satisfactory information from the provider on the issues relevant to you, on a scale of one to ten; (9) if your answer to the previous question was less than ten, what would you like to have had covered that wasn't; etc.

Thank you for the opportunity to comment on this important health and safety initiative.

Respectfully submitted,

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