

Date: May 2, 2016.

Mike MacPherson,
Clerk to the committee
JUST@parl.gc.ca

RE: Amendment to section 241.31 (3) of Bill C-14

Dear Mr. MacPherson:

I am writing very specifically regarding the commitments to monitor and evaluate the impact of proposed medical assistance in dying legislation, as discussed here: <http://www.justice.gc.ca/eng/cj-jp/ad-am/faq.html> . My concern relates to the nature of research and data with respect to persons who are at the margins of our society. These individuals are also more likely to be vulnerable to a devaluation of their life or the conditions of their life. They are the individuals that may be subject to implicit and explicit social pressures to speed dying.

Individuals who are outliers are traditionally considered “noise” in a data set, or normed out of the data in the attempt to analyze and draw conclusions from the data. If you are different from the norm you are not represented by data that has statistical power as a threshold. Another condition of traditional research is that the conditions under consideration be isolated to arrive at verifiable conclusions. The conditions under which a decision is made to end your life, especially if you are an outlier, are never clear-cut, but hugely complex and entangled.

I would encourage the committee to consider methods of monitoring, evaluation and analysis that support the diverse and complex conditions under which these decisions are made and supported. This would involve less traditional research methods that do not privilege the norm, including “small”, “thick” data research, indigenous research methods and diversity supportive research.

We need to ask questions about the nature of the suffering that motivates the request and the range of interventions (medical, social, technological, spiritual, emotional, innovative and non-traditional, etc.). We need to track this information for everyone who makes a request, whether or not it is ultimately granted and whether or not it is ultimately administered. I’d also encourage endorsement of the five safeguards assembled in the Vulnerable Persons Standard.

Sincerely,

Jutta Treviranus
Director, Inclusive Design Research Centre
OCAD University
<http://idrc.ocadu.ca>