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To whom it may concern,

I am an Associate Professor in the Department of Medicine of the University of California, San Diego. I have been conducting research on the prevention of overdose and blood borne virus transmission among people who use drugs in Australia, the United States, and Mexico since 1997. Please find following my expert review of the Kanawha-Charleston WV Harm Reduction Program audit report.

The overarching purpose of any Syringe Services Program (SSP) anywhere in the world is primary prevention, and the gold standard approach to achieving that purpose revolves around low threshold access. By this I mean that decades of research have demonstrated that SSPs are most effective at preventing the spread of HIV and other blood borne viruses when they concentrate on providing enough syringes to people who use drugs for them to use a new syringe for every injection, and avoid doing anything that impedes that goal in any way.

My main observation is that, as written, the current 'Conclusions and Recommendations' of the Audit report of the Kanawha-Charleston WV Harm Reduction Program appear to see the primary purpose of SSPs as being data collection and the integration of service users into a broader medical system, so much so that primary prevention becomes almost an afterthought. As a consequence of this framing, almost all of the Recommendations in the Audit represent severe and in some cases unconscionable barriers to effective, evidence-based, primary prevention of blood born virus transmission.

I have two further comments about the purpose of SSPs and the role of data collection at SSPs.

The highest risk individuals for acquiring or living with HIV and other blood borne viruses are people who are currently unable or unwilling to interact with other health services. This unwillingness may be due to past poor experiences with healthcare systems, or due to fear of police, or due to druginduced or mental illness-induced paranoia. SSPs represent unique opportunities to respectfully engage with such individuals, to provide essential primary prevention supplies, and to (often slowly) build the trust relationships necessary to facilitate effective referrals to other highly desirable services such as drug treatment. In this unique setting, extensive 'patient registration' and/or data collection efforts act as explicit barriers to service access. SSPs exist because other parts of the healthcare system have failed to provide these members of the community with supportive and effective service provision, and requiring that an SSP take on the characteristics of other healthcare services which have driven people who use drugs away (eg patient registration) will simply lead to drug users receiving no HIV prevention services.

Secondly, as a medical researcher, I value data enormously. However, for research to be ethical, the benefits of collecting data must be commensurate with the risks associated with collecting data. Collecting data from service users at SSPs comes with well known risks – namely that some service users will not be willing to access the SSP due to drug-induced paranoia, mental illness, and/or fear of police (often those at highest risk of acquiring or living with HIV and other blood borne virus transmission), and that data collection activities can represent considerable burdens on often underresourced SSPs, reducing the resources and time available for actual service delivery. As such, for a research or surveillance project conducted at an SSP to be ethical, the benefits of any data collection need to be such that they justify the above risks and burdens, and data collection should be the minimum possible to achieve a well articulated and clear research or surveillance question, and where possible, be both time limited and involve directly questioning service users as little as possible. Collecting data indefinitely with no clear, articulated, high benefit purpose is inherently

unethical.

SSPs, due to their controversial nature, are one of the best studied public health interventions of the past four decades. There are few overarching research questions relating to SSP efficacy or impact that have not already been extensively documented in the literature. As such, unless new questions which are not already addressed in the literature emerge, data collection should be limited to, at most, documenting number of syringes distributed and counting the number of individuals served. Even here, thought should be given to limiting such data collection to periodic data collection (e.g., two weeks of data collection conducted every third month) rather than continuous data collection in order to minimize the burden on SSP resources. Obviously, any externally-required data collection should be funded above and beyond normal SSP funding to avoid cutting into essential primary prevention services.

I am happy to be contacted for more detail on any of the above points.

Sincerely,

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