Comment Form: Developing Consent Language for Research Using Digital Health Technologies

I am responding:	on-behalf-of-an-organization
Name	Tayler Williams
Name of Organization	American Medical Informatics Association (AMIA)
Type of Organization	professional-organization-association
Type of Organization - Other	
Role	organizational-official
Role - Other	
Domain of research most important to you or your organization (e.g. cognitive neuroscience, infectious epidemiology)	Medical Informatics
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2	The skeleton wording leaves a significant amount for the individual team to adapt in describing their intervention/device. AMIA would want to ensure that samples of how to describe certain technologies be developed to reduce the risk of jargon being used (i.e., could see a team giving names of products that don't have meaning to the potential participant).
2	1) With the wording related to de-identification is there, AMIA is interested about devices that have location or other individual-specific data collected, and how to have the researcher be transparent about whether the data is 'truly' de-identified or just name/DOB type information is removed, or if re-identification is possible when triangulated with other data. 2) AMIA notes a potential concern about the relatively sparing wording that essential says, 'refer to the companies' policies'. How likely is a participant to go and access that company to see what the data sharing they employ is? Or that they would be able to find it? I'm not sure the ideal wording, but seems important to consider greater transparency here, especially as this is one of the risks that does not start and end within the research team, and therefore could have greater risk of reducing participant trust in the process. 3) The timeframe of data sharing may be important in some cases (i.e., is data shared in one bundle at the completion of participation or in real time?).

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