Implementing benefits and payments guidelines for research and engagement work: Experience from the KEMRI-Wellcome Trust Research Programme (KWTRP)

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Provision of benefits and payments to research participants, informed by ethics guidelines and principles, is common practice but ethically controversial. It is agreed that participation should not be exploitive to participants, and payments to participants - including compensating for time, expenses, and inconvenience - are widely accepted. However, there are concerns that payments may over-commercialize what some see as an altruistic endeavor, undermine decision-making (through acting as an ‘undue inducement’), and compromise informed consent. Determination of types and levels of payments is challenging as ethics guidelines offer limited operational guidance. We will share our experiences of developing and implementing the KEMRI Wellcome Trust Research Programme’s (KWTRP) benefits and payments guidelines. The Guidelines were first developed in 2015, informed by empiric studies. The guidelines aimed at supporting KWTRP researchers to plan participant benefits and payments and strengthen approaches to discussing them within consent and community engagement processes. They prompt researchers to consider benefits and payments during protocol development and provide guidance for determining potential benefits and payments across different types of studies, while allowing for flexibility to unique circumstances. A Communication and Consent Committee (CCC) reviews and advises researchers on consent and engagement aspects, is often involved in deliberations about payments. The guidance documents are limited in several ways. For example, they do not cover Phase 1 and Challenge studies, which bear relatively high risks and inconveniences. For these studies, high payments for time and inconvenience can be perceived as undue inducements or paying for risks. It is also unclear how to appropriately compensate professionals recruited for their skills. The approach we are using is review of literature, deliberations within CCC and discussions with researchers. We are however cognizant of the tensions between the guiding principles of consistency, fairness, equity and safe-guarding participants’ autonomy. In conclusion, standardizing systems on participants payments is meant to minimize exploitation and undue inducement, but its application is far from straightforward. It is paramount, especially for long-standing institutions operating in the same context to regularly revise guidance in response to changing environments.