

Attitudes towards payment and payment practices in human infection studies

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Background

Human Infection Studies (HIS) are research trials involving the infection of otherwise healthy participants with disease.

HIS are critical tools employed in medical research to study the causation of disease, incubation, symptomology and importantly, to progress vaccine development. The payment of HIS participants is a problematic issue (Figure 2) that has attracted public debate but has not been discussed in depth in current ethical and medical literature. Currently little is known of what research groups are paying participants or what principles they use when devising payment plans. Furthermore, there have been no formal empirical studies that have explored the attitudes towards payment in HIS.

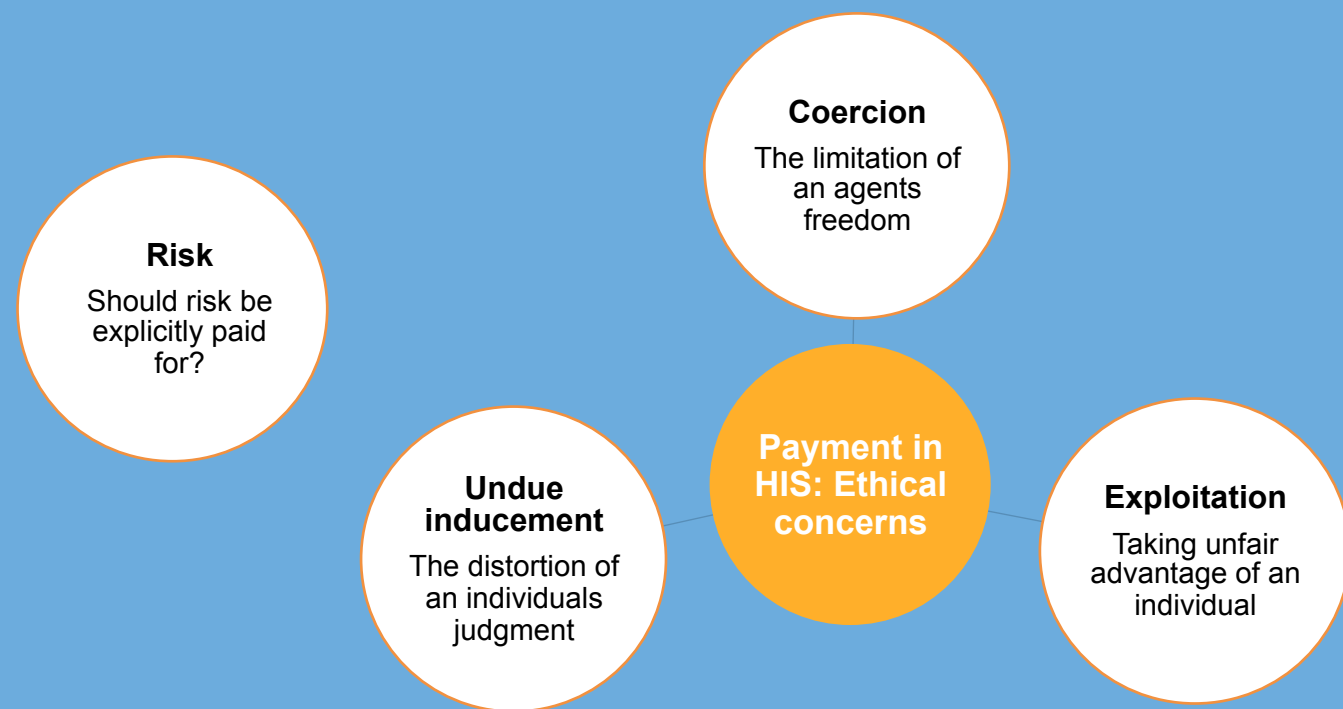


Figure 2: Ethical Concerns surrounding Payment in HIS

Key Findings

Empirical: The survey collected 264 valid responses.

- Respondents believed HIS participants should be paid significant amounts of money and that the risk involved in a HIS should be explicitly accounted for in the payment (Figure 3, Table 1)
- Many respondents somewhat agreed that high payments could potentially pose risks of undue inducement (71.6%) and coercion to participants (57.2%). However, the actual concern surrounding these issues did not lead to respondents limiting the level of payment offered to HIS participants in hypothetical scenarios.
- The most preferable payment models were a “Wage and Risk Payment Model” and a “Market Model”.

Ethical Analysis: The time commitment, the location of the study, the pain experienced and the risk involved are all critical payment factors that investigators should consider when aiming to devise an ethical payment plan for their HIS participants.

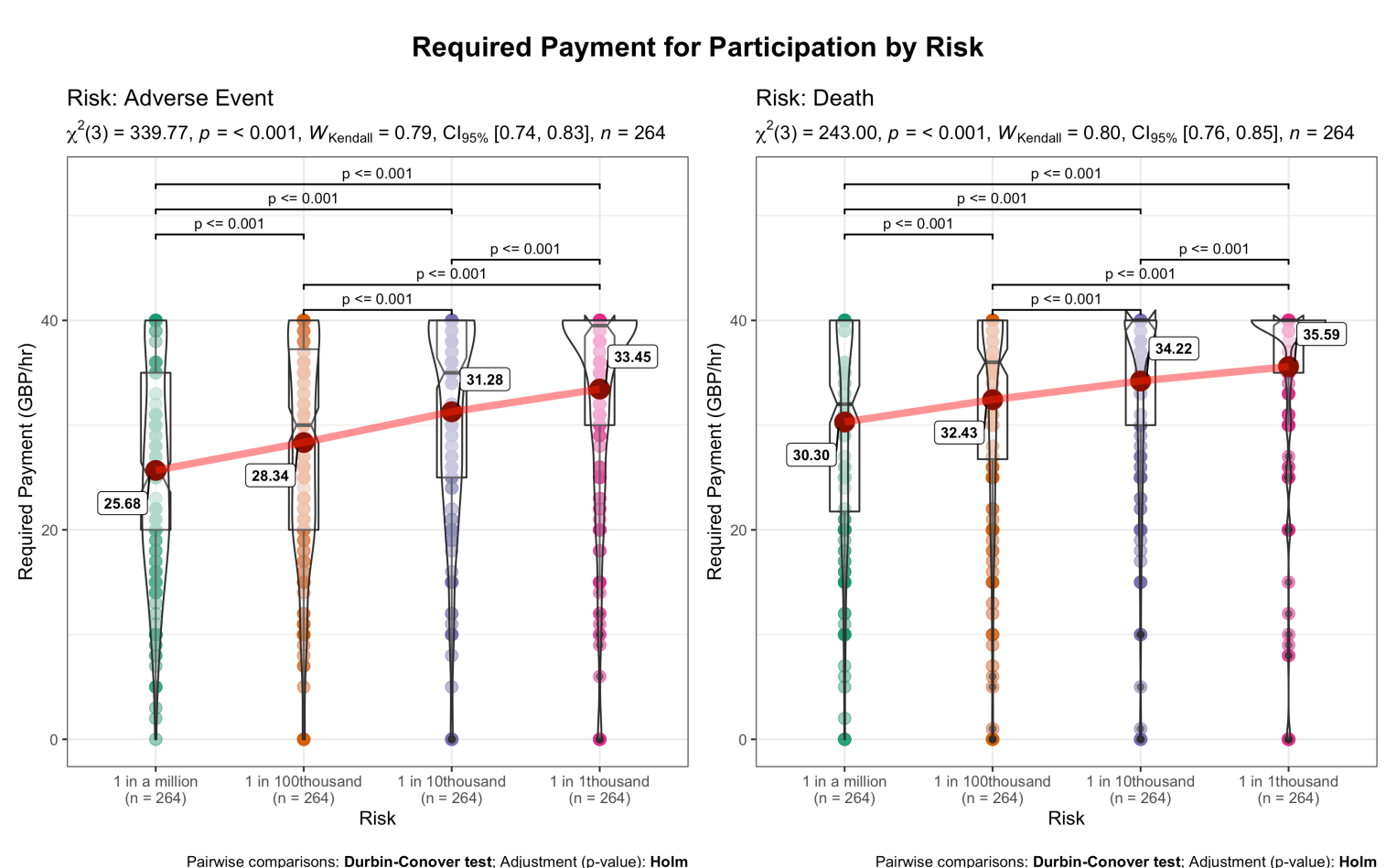


Figure 3: Required payment for participation by risk level and risk category

Aims

This project integrates empirical data with ethical analysis. There are two primary aims:

1. To collect **empirical data** that assesses the attitudes between the public and HIS investigators towards payment in HIS, and the specific payment practices and principles in HIS (Figure 1).
2. To perform an **ethical analysis** of my empirical data and to suggest a framework that outlines how to devise ethically justifiable payment of HIS participants.

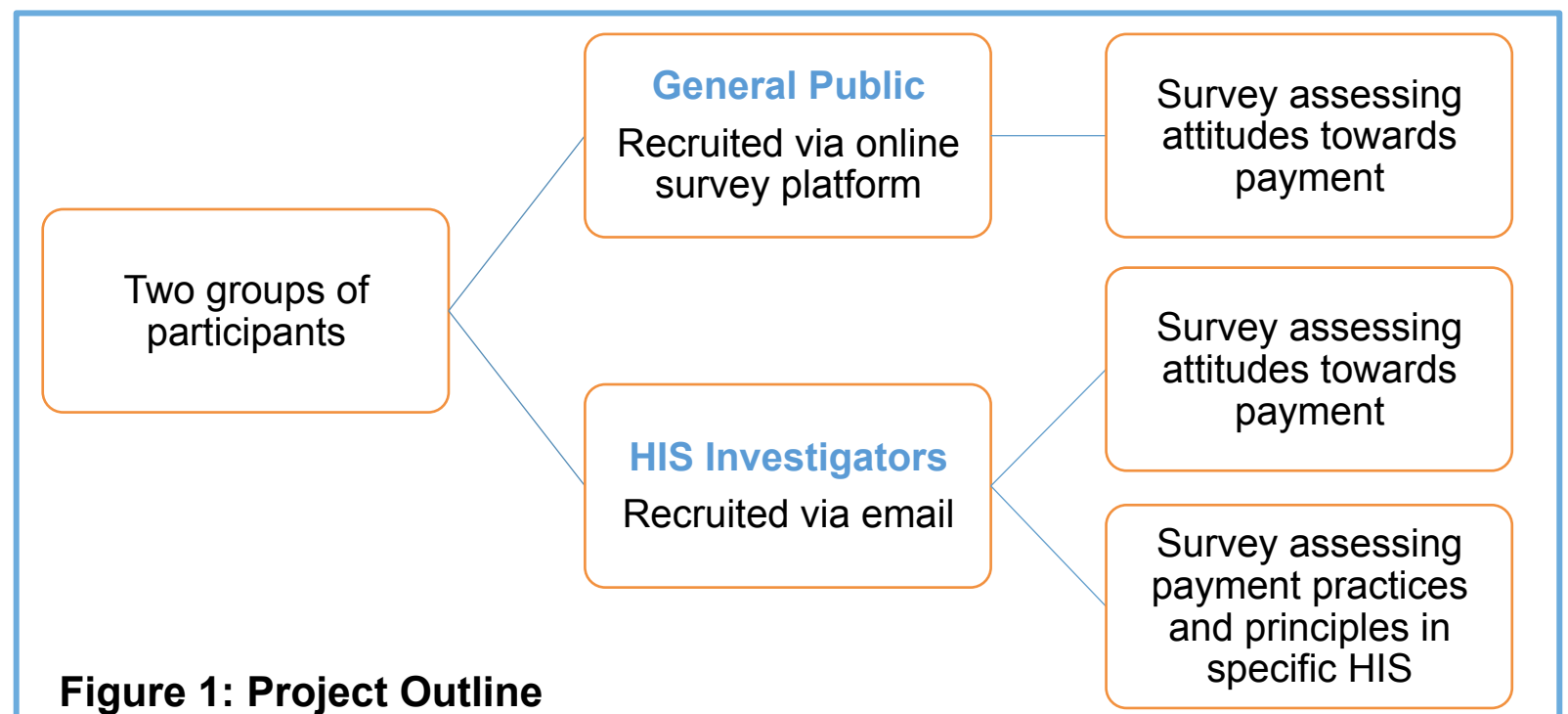


Figure 1: Project Outline

Methodology

Empirical:

- Online survey of a representative sample of the UK public
- Survey comprising of hypothetical vignettes and direct attitudinal questions
- Assessing opinions of payment for risk in HIS, payment models and payment as coercion and undue inducement

Ethical Analysis:

The prominent philosophical stances to the ethical issues raised by payment of HIS participants were identified through the literature review and then were carefully considered and compared to my empirical data through the process of reflective equilibrium.

Payment factor	Mean rank of importance
Risk of serious side effects and death involved in the study	1.24 (0.80)
Pain involved in the study	2.48 (0.86)
Number of invasive investigations involved in the study (for example blood tests, investigations requiring sedation)	3.18 (1.01)
Time required in the study	4.29 (1.43)
Number of non invasive investigations involved in the study (for example urine sample, saliva swab, ultrasound)	4.95 (1.00)
Inconvenience involved in the study	4.97 (1.12)

Table 1: Mean rank of importance of payment factors

Conclusions

- It is ethically justifiable to **pay for the risk** HIS participants encounter.
- The concerns of coercion and undue inducement are not sound reasons for limiting payment in HIS but are instead wrongly preventing the fair compensation of HIS participants.
- A **“Wage and Risk Payment Model”** that carefully considers a number of different critical payment factors, is the best model to deliver just payment to HIS participants and to decrease the likelihood of exploitation or underpayment.

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