# Incentives in Diabetic Eye Assessment by Screening (IDEAS): a three-armed randomised controlled trial of financial incentives

# Authors:

Gaby Judah<sup>1</sup>, Ara Darzi<sup>1</sup>, Ivo Vlaev<sup>2</sup>, Laura Gunn<sup>3</sup>, Derek King<sup>4</sup>, Dominic King<sup>1</sup>, Jonathan Valabhji<sup>5</sup>, Lisa Bishop<sup>6</sup>, Adrian Brown<sup>7</sup>, Grant Duncan<sup>6</sup>, Anna Fogg<sup>6</sup>, Gemma Harris<sup>7</sup>, Peter Tyacke<sup>7</sup>, Colin Bicknell<sup>1\*</sup>

# Affiliations:

<sup>1</sup>Department of Surgery and Cancer, Imperial College London, UK
<sup>2</sup>Warwick Business School, University of Warwick, UK
<sup>3</sup>Department of Integrative Health Science, Stetson University, USA
<sup>4</sup>Personal Social Services Research Unit, London School of Economics & Political Science, UK
<sup>5</sup>Imperial College Healthcare NHS Trust, St. Mary's Hospital, UK
<sup>6</sup>1st Retinal Screen Ltd, UK

<sup>7</sup>NHS England, UK

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# **Scientific summary**

# Background

Diabetes is estimated to currently affect over eight per cent of the global population. The cost of treating diabetes and its complications is estimated to cost ten per cent of the NHS budget. This is primarily due to the major complications of neuropathy, nephropathy and retinopathy as well as complications of ischaemic heart disease, stroke and limb loss as diabetes is a major risk factor for generation and progression of atherosclerosis,

One of the micro vascular complications of diabetes is diabetic retinopathy, which can affect patients with Type 1 and 2 diabetes. This complication is characterised by the growth of new, fragile blood vessels in the eye, which cause significant retinal damage from micro haemorrhage, leading to sight loss. In England every year there are 1,280 new cases of blindness from diabetic retinopathy, which is one of the leading causes of blindness in the working age population in England. Early diagnosis and treatment of retinopathy significantly reduces the risk of blindness. Therefore, everyone in England with diabetes (aged twelve and over) are offered annual diabetic retinopathy screening by the Diabetic Eye Screening Programme (DES). The rate of screening uptake is 81%, leaving many people at risk of avoidable sight loss. Furthermore, screening rates are lower in more socially deprived areas. Therefore, simple, cost-effective strategies are needed to achieve the full benefits of screening, and to do so in an equitable way.

There is increasing interest in using financial incentives to encourage healthy behaviours. Evidence suggests that incentives may be more effective at promoting infrequent behaviours (e.g. vaccinations) compared to frequently performed behaviours (e.g. smoking). Therefore, incentives could be expected to be an effective strategy to promote screening uptake. The impact of financial incentives in screening is variable, and has not previously been investigated in a randomised trial of DES uptake.

Financial incentives are sometimes thought of as controversial, as they could be seen as a form of coercion. However, appropriate incentives could reduce inequalities in health outcomes. Furthermore, incentives may be seen as a way to help people align behaviour with their underlying intentions, so therefore enhance rather than reduce behavioural autonomy. Incentives could be better perceived as acceptable if they are effective and cost-effective, and if they benefit participants and wider society.

The design of financial incentive schemes impacts upon their effectiveness. The field of behavioural economics provides robust psychological phenomena, which explain and predict behaviour. One principle considered in the design of the incentives for this study was 'reference points' which indicates that small incentives can have an impact upon behaviour, but there is little additional advantage to increasing the level of incentive. Therefore, one incentive in this study was selected to be £10, to cover time or travel costs of the patient.

The second key principle used to inform the design of the trial incentives was the 'overweighting of small probabilities' whereby people are likely to overvalue small probabilities. This explains the popularity of lotteries and insurance. The use of lotteries in incentive schemes can be a more effective way of using limited resources compared to smaller individual rewards. Work conducted by the trial team prior to this study final design determined that people might be categorised as risk avoiders, or risk seekers (favouring the riskiest option with the highest potential payoff). Therefore, a lottery incentive was selected to represent the highest level of incentive that could be provided by the trial funding, which would represent the same average payoff as the fixed incentive. This was a one in one hundred probability of winning £1000.

#### **Objectives**

To test whether financial incentives are an effective strategy to encourage participation in the screening programme. Secondarily to understand whether the design of the financial incentive scheme used affects its effectiveness in influencing participation in health screening uptake or attracts patients who have a different demographic or sociodemographic status to those who attend screening regularly. If financial incentives improve attendance a final objective was to test if these could be cost effectiveness if rolled out on a population wide basis.

## Methods

#### **Participants**

Eligible participants were identified by the screening provider, 1st Retinal Screen Ltd, prior to the start of the study. In order to be eligible, participants had to be in the geographical area due to be invited for screening (defined as the GP of the patient being within Kensington, Chelsea or Westminster). Participants also had to be aged sixteen or over, and have failed to attend screening for at least two annual appointments, or to have failed to contact the screening service to try and rearrange their appointment.

As the usual invitation process continued for patients in the trial, a minimum twomonth window was left between any contact as part of usual care, and invitation into the trial, in order to avoid contacting participants who were late to contact the screening service but who still intended to do so. In order to ensure that the contact details were correct, participants were excluded if a post-office return had been received from their address. Participants were selected based on these criteria using an electronic search of the screening provider database. In order to further verify that correct details were used, and only eligible patients were contacted, the study population was checked against the patient register immediately prior to invitation to the trial.

## **Design and procedure**

The study was a three-arm randomised controlled trial. The impact of two different types of financial incentives was compared to a control group, who were sent the usual appointment invitation letter. Participants were randomised at the start of the study by the statistician to the three arms according to a 1.4:1:1 randomisation ratio,

in order to achieve maximum statistical efficiency. Appointment invitation letters were sent to participants four weeks prior to a planned trial appointment date.

The study took place at a diabetic retinopathy screening clinic within St Mary's Hospital, in London, which is part of Imperial College Healthcare NHS Trust. Dedicated clinics were held for each of the three conditions, in order to avoid patients becoming aware of incentives being offered in the different trial conditions. Participants could rearrange their appointment once if necessary, and still be eligible for the incentive.

# Conditions

#### **Control**

This group received the usual appointment invitation letter, inviting patients to a fixed appointment at a particular date and time.

## **Fixed incentive**

This group were sent the usual invitation letter, including a voucher for £10 if they attend their appointment. The fixed incentive was paid in cash by the researcher at the screening clinic.

#### Lottery incentive

This group were sent the usual invitation letter, including a voucher for a 1 in 100 chance of winning £1000 if they attend their appointment. The lottery was conducted following each lottery clinic using a computer program, which gave each attending participant a 1 in 100 probability of being selected as a winner. If no winners were selected in this way, one winner was planned to be selected at random at the end of the study, from all attenders from the lottery group.

## Measures

Following completion of the study, the dataset was generated by the data manager at 1st Retinal Screen Ltd, using a database search of their system to extract all relevant attendance and demographic data.

The primary endpoint of the study was the proportion of invitees who attended screening. Demographic information was collected for all invited participants on gender, age, deprivation (measured using the Indices of Multiple Deprivation (IMD) score), years registered and distance from home to the screening centre. If participants were excluded from the trial after randomisation, but before being invited, the reason for this was recorded. These reasons were categorised within the final dataset to facilitate comparisons. For those participants who attended their screening appointment, data on their screening outcome score was collected, and aggregated by intervention group. When patients attended their appointments, the screener asked them for any reasons why they have not attended their past few appointments, in order to see if there are differences between intervention groups, and to explore common barriers to attendance in this hard-to-reach group.

Demographic details were also collected for the patient population who were not invited to the trial, in order to compare the IDEAS study population with the remainder of the retinopathy screening cohort. This non-trial population were categorised as to whether or not they are regular attenders at screening (defined as having attended at least twice in the past three years).

#### Analysis plan

The primary outcome was the attendance rate by treatment group, compared using Chi-square tests. Risk differences and risk ratios, are presented to assess whether any significant differences between groups exist.

Further exploratory subgroup analyses were conducted to explore the third research question about whether the incentive schemes attract patients with a different socioeconomic or demographic status. Comparisons were made to those who are classified as regular 'current' attenders to assess possible differences through demographic covariates between regular attenders and non-attenders.

A pre-planned cost-effectiveness analysis would determine whether the intervention was a cost-effective way to increase screening.

#### Results

Of the 1,274 patients who were deemed eligible and randomised, 223 became ineligible before being sent the invitation letter. (The most common reason for this was attending their screening appointment prior to the trial.) This left 1051 invited participants, 435 in the control group, and 312 and 304 in the fixed and lottery groups respectively. There were no significant differences between groups in age, gender, deprivation score, distance from clinic, or years registered.

A smaller proportion of trial patients were above the age of 65 compared to regular attenders from the general screening population, however a larger proportion were older than 65 compared to non-regular attenders from the general population.

Considering the primary outcome, 7.8% control participants, 5.5% from the fixed group and 3.3% from the lottery group attended screening. Those in an incentive group were 44% less likely to attend screening than controls (RR=0.56; 95% CI 0.34, 0.92).

Examining differences between incentive groups showed those in the lottery group were 58% less likely to attend screening than controls (RR=0.42; 95% CI 0.18, 0.98). No significant differences in attendance were found between fixed incentive versus control (RR=0.70; 95% CI 0.35, 1.39); or fixed versus lottery incentive groups (RR=1.66; 95% CI 0.65, 4.21).

There were no significant differences in sociodemographic variables between attenders and non-attenders. There were no significant differences between attenders in the control or incentive conditions.

Of the sixty participants who attended their trial appointment, 78% did not require any additional management aside from annual recall to screening (82% from the control group, and 73% from the incentive groups). Chi-square analysis (p=0.387), along with pairwise comparisons verified that there were no significant differences in whether additional management was recommended between the different randomised groups.

Reasons for past non-attendance were split into three categories: organisational problems, practical/logistical problems, and not thinking they needed to be screened. A Chi-square analysis revealed no significant association between reason for non-attendance and belonging to the control group versus the incentive groups (p=0.119). Half the participants who should have attended screening in the past stated they did not attend past appointments due to organisational reasons, while a quarter each selected practical/logistic problems and that they didn't think they needed to attend.

A sensitivity analysis was performed which excluded any participants who had a reason for ineligibility following the invitation letter being sent. Similar results were obtained showing the incentive group were 52% less likely to attend screening than controls (RR=0.48; 95% CI 0.29, 0.80). Those in the lottery group were 58% less likely to attend screening than controls (RR=0.42; 95% CI 0.18, 0.97). Again, no significant differences in attendance were found between fixed incentive versus control (RR=0.54; 95% CI 0.25, 1.16); or fixed versus lottery incentive (RR=1.30; 95% CI 0.49, 3.49).

A second sensitivity analysis included as attenders participants who needed to arrange their trial appointment but were booked onto normal screening as they could not attend on another trial clinic day. This analysis showed a significant, though weak, difference in attendance between the incentive group and controls (RR=0.63; 95% CI 0.40,0.99); there was no significant difference in comparisons between any other groups.

#### Conclusions

The numbers attending retinopathy screening were low, with attendance rates of 7.8% in the control group, 5.5% in the fixed incentive group (£10), and 3.3% in the lottery incentive group. Unexpectedly, the incentive groups combined were less likely to attend screening than those who received a standard appointment invitation. Considering each incentive scheme separately, the lottery group were less likely to attend than those in the control group (there was no significant differences between the control and fixed incentive group). Incentives were therefore not effective or cost-effective at improving screening uptake in poor attenders at DES.

The sociodemographic characteristics (age, gender, deprivation, distance from screening centre, or years registered) of attenders were not different from those not attending. There were also no sociodemographic differences between attenders from the control and incentive groups.

One explanation for the observed negative effect may be that being offered an incentive for a health check may elicit feelings of dread, through making people think

the appointment must be unpleasant if they are being paid to attend. This could make them less likely to attend. The fact that the lottery, which offered a high value incentive, had significantly worse attendance rates, supports this theory, as the larger incentive may have promoted greater feelings on dread than the more modest £10 incentive offer.

The results were unexpected, as negative effects of incentives are uncommon, and on the whole, incentives have been found to be effective at promoting screening. However, a previous cohort study observed that offering financial incentives for diabetic retinopathy screening was associated with significantly lower attendance rates. This therefore supports the present findings that financial incentives may be detrimental in promoting diabetic retinopathy screening.

The results indicate the importance of testing interventions in context even if they are supported by theory, or appear to be effective in other contexts. (For example, incentives may have a different effect in the USA compared to the UK, as people in the USA are more accustomed to financial transactions in healthcare.)

As financial incentives do not appear to be a promising avenue to explore for promoting diabetic retinopathy screening, future research should focus on investigating barriers to adherence, and other methods for effectively overcoming these in order to promote greater attendance.

Study registration: ISRCTN14896403