Acceptability of offering financial incentives to achieve medication adherence in patients with severe mental illness: a focus group study

Stefan Priebe,[1] Julia Sinclair,[2] Alexandra Burton,[1] Stamatina Marougka,[1] John Larsen,[3] Mike Firn,[4] Richard Ashcroft[5]

[1]Queen Mary University of London, Unit for Social and Community Psychiatry, Newham Centre for Mental Health, London, UK
[2]Division of Clinical Neurosciences, Royal South Hants Hospital, Southampton, UK
[3]Rethink, London, UK
[4]South West London & St George's Mental Health NHS Trust, Springfield University Hospital, London, UK
[5]Queen Mary University of London, London, UK

Correspondence to
Dr Stefan Priebe, Professor of Social and Community Psychiatry, Unit for Social and Community Psychiatry, Newham Centre for Mental Health, Glen Road, London E13 8SP, UK;
s.priebe@qmul.ac.uk

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ABSTRACT

Background Offering financial incentives to achieve medication adherence in patients with severe mental illness is controversial.

Aims To explore the views of different stakeholders on the ethical acceptability of the practice.

Method Focus group study consisting of 25 groups with different stakeholders.

Results Eleven themes dominated the discussions and fell into four categories: (1) 'wider concerns', including the value of medication, source of funding, how patients would use the money, and a presumed government agenda behind the idea; (2) 'problems requiring clear policies', comprising of practicalities and assurance that incentives are only one part of a tool kit; (3) 'challenges for research and experience', including effectiveness, the possibility of perverse incentives, and impact on the therapeutic relationship; (4) 'inherent dilemmas' around fairness and potential coercion.

Conclusions The use of financial incentives is likely to raise similar concerns in most stakeholders, only some of which can be addressed by empirical research and clear policies.

INTRODUCTION

Maintenance antipsychotic medication has been shown to be effective in the treatment of patients with psychotic disorders. It was unequivocally recommended by the National Institute for Clinical Excellence (NICE) guidelines,[1] yet adherence to medication remains problematic. Several strategies (eg, compliance therapy, psychotherapy, psychoeducation) have been tested to improve adherence, but have been shown to have, at best, a limited effect.[2 3]

Hospital re-admission,[4] social withdrawal, low quality of life and disruptive or self-harming behaviour[5] have been identified as some of the possible consequences of non-adherence to medication. In an analysis of serious untoward incidents in England,[5] non-adherence to treatment was a feature of at least one-quarter of suicides and homicides by people with mental illness. New strategies are therefore required to achieve medication adherence in some patients with psychotic disorder.

However, adherence to antipsychotic medication is a concept that provokes strong reactions. First, it raises the concern that non-adherence represents an autonomous choice, deserving respect and protection in itself. On this account, the very idea of adherence is a weakly disguised paternalistic notion. It is a problem only for the doctor, whose patient is resisting adhering to expert advice. Second, non-adherence may indicate a reasoned decision not to take medication in order to avoid potentially serious side effects. Third, it may indicate a reasoned decision not to take medication on the basis that the patient disagrees with the negative valorisation on the illness experience, and with the diagnosis itself. There is merit in all of these views, but they overlook the real and dangerous consequences of non-adherence, and the extent to which patients themselves endorse their diagnosis and treatment plans but find adherence difficult in practice.

Another concern about the use of antipsychotic medication relates to the role of coercion in psychiatric treatment, through both legal and informal means. Finding means to encourage adherence to treatment that are not coercive is important. Some methods of treatment are more coercive in their effect than others; a depot medication ties a patient into a course of treatment for a longer time without the possibility of stopping treatment than does daily pill-taking. Even if it is conceded that psychiatric treatment can be inherently coercive, given the nature of psychiatric diagnosis and the background availability of coercive powers enshrined in law, there is still value in engaging the patient as an autonomous person and of using minimally coercive means of engagement and treatment so far as possible.[6]

Evidence from the USA demonstrates that financial incentives can substantially improve adherence to treatment in various medical conditions.[7] There is little literature on their use to achieve medication adherence in patients with psychotic disorders.[8] Out of five patients where adherence had not been achieved by any other means in East London,[9] four accepted financial incentives and had improved medication adherence with favourable clinical outcomes.

The report triggered an intensive debate on whether offering financial incentives to achieve medication adherence in patients with psychotic disorders is acceptable.[10] In a survey of assertive outreach team managers[11] 42% felt that offering incentives would be 'unethical'. Arguments presented by Szmukler (2009) on the use of financial incentives included 'coercion' of the patient, 'incommensurable values' whereby the offer of financial incentives degrades 'an aspect of respect for the person', 'exploitation' of the patient and

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'fairness' of offering financial incentives to some patients and not others.[12] Others claim that financial incentives should be interpreted as a reward and are less coercive than existing forms of leverage, such as enforced hospital admission.[13] Before a wider application of financial incentives in patients with psychotic disorders is considered, it appears essential to identify the attitudes, concerns and opinions of different relevant stakeholder groups in mental healthcare. This study aimed to explore and understand such views in a systematic manner using a qualitative methodology.

METHOD

Data were collected using a focus group methodology, as this allows the exploration of participant attitudes and opinions, as well as facilitating the generation and specification of ideas on a defined topic. Purposive sampling was used to include as wide a range of relevant stakeholder groups as possible.

Participants

Staff and patients from community mental health teams and assertive outreach teams were recruited to 18 focus groups. The teams cover inner city, suburban and more rural areas, with different levels of deprivation. We also recruited non-executive directors of a Mental Health Trust, patient forum representatives, health economists, family and informal carers, and voluntary organisation representatives (the final two through the mental health charity organisation Rethink).

Consultant psychiatrists and trainee psychiatrists were identified through staff lists. For the recruitment of other staff, we approached 18 community mental health teams and nine assertive outreach teams. Eighteen teams expressed an interest in participating. We presented the project at existing team meetings. One team declined participation. Staff names and contact details were obtained from the team managers. An invitation to participate in a focus group was then sent to staff via email and followed up with a telephone call. Service users were approached by staff and/or team managers to participate in one of two focus groups, while a third group were recruited through their links with a patient forum.

Procedure and data collection

Focus groups were conducted between November 2007 and December 2008. Each group lasted approximately 1 h and had between three and 10 participants. All groups were conducted by an experienced facilitator and co-facilitator, digitally recorded and later transcribed verbatim. All followed the same procedure. After the initial introduction of all participants, the facilitator presented the following research question to the group: '*What are your initial thoughts on paying non-adherent seriously mentally ill service users to take their medication?*', which was discussed for 10–25 min. Following this, a case vignette describing a patient with a psychotic disorder and problematic medication adherence was introduced. The vignette was deliberately left vague to help participants express their own views and ask questions of the scenario. The facilitator encouraged the participants to explore alternative arguments to those presented within the group, and if appropriate, the participants were challenged on their views. The vignette is presented in box 1.

Analysis

Data collection and analysis occurred simultaneously and focus groups continued until all key stakeholder views had been represented and saturation of data was reached. Three of the researchers (JS, AB, SM) repeatedly read the first six transcripts and independently defined a preliminary coding scheme, which was discussed in the research team. The final coding scheme was generated by an iterative process as further data were collected until saturation was reached. Data were analysed by the researchers independently reading the transcripts and coding all material using NVivo7 (QRS) software, with continuous comparison and discussion where discrepancies arose. The codes were then linked and collapsed into broader themes. The research team discussed and analysed the link between the early dense codes and broader themes to ensure conceptual clarity and consistency across the themes and further recoding where required.

Box 1 Case vignette used to stimulate focus group discussions

A 25 year old person with a 6-year history of severe mental illness has been admitted to hospital on three occasions. On two of these the person was detained against their own will, although legally.

The person agrees to take medication (depot) when staying in hospital and for a few months after discharge. However, the person starts to become unavailable at the time of the depot, and then refuses the medication.

At the same time, the person also stops attending a work skills group, and is no longer taking care of personal hygiene or looking after the flat properly. This leads to the landlord throwing the person out of the flat, and a period of time when the person becomes mentally very unwell again. If the person's mental health does not improve, hospital admission seems necessary.

Should the person be offered payment to take the medication?

RESULTS

Sample

A total of 25 focus groups were carried out with 139 participants, including 27 service users, 16 carers, 76 community mental health or assertive outreach team staff, and 20 other mental health service stakeholders. The sample captured a range of experience of staff with the mean length of service being 13 years (ranging from 5 months to 30 years). Patients had been using mental health services for an average of 15 years (ranging from 4 to 30 years). Twenty-one groups contained a homogenous sample of the following participants: patients (five groups), carers (three groups), consultant psychiatrists (three groups), psychiatrists in training, nurses (two groups), social workers and occupational therapists, psychologists, community team managers, voluntary organisation representatives, patient forum representatives, health economists and non-executive directors of a mental health trust. Four groups were each run with staff from an existing team to reflect a natural multidisciplinary team setting. Participants were aged between 21 and 76 (mean 43) years and 55% of the sample was female.

General results

Although groups varied substantially in their atmosphere, exact discourse and aspects of the argument, there was a high level of saturation across the groups regarding the content of the concerns raised. Nearly all of the major themes were brought up in every group.

The transcriptions generated a total of 23 codes, which informed further analysis and identification of 11 major themes

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describing the key discussion threads of the groups. Themes fell into one of four main categories depending on the nature of the concern and the possibilities to address and further explore them. The categories consisted of 'wider concerns', 'problems requiring policies', 'challenges for research and experience' and 'inherent dilemmas'. The categorisation did not consider how serious, important or complex the themes were. The focus groups, the four categories of themes, and all themes with illustrating quotes are summarised in figure 1.

Wider concerns

Four major themes reflected wider concerns that were linked to the issue of financial incentives. These themes went beyond the specific clinical problem and concerned more general issues associated with it.

There were some very critical views on the value of medication in psychiatric treatment, expressed with particular intensity by psychologists and some patients. They felt that medication should be prescribed with more caution, if at all, and that a 'medical model' was too dominant in mental healthcare.

The question as to where the money for the provision of incentives would come from led to concerns that other important services and interventions might suffer financially if money were spent on incentivising patients.

Further concerns were raised that patients may use the money to buy drugs and alcohol, which may then have a negative impact on their mental health. Some participants thought that if it could be ensured that the money was used for therapeutic purposes, such as accessing recreational activities, then such a practice would be more acceptable.

Finally, there were repeated assumptions, particularly in non-clinician groups, that the idea of offering financial incentives was brought up by the 'state' or more specifically the 'government' to control patients and save money by reducing

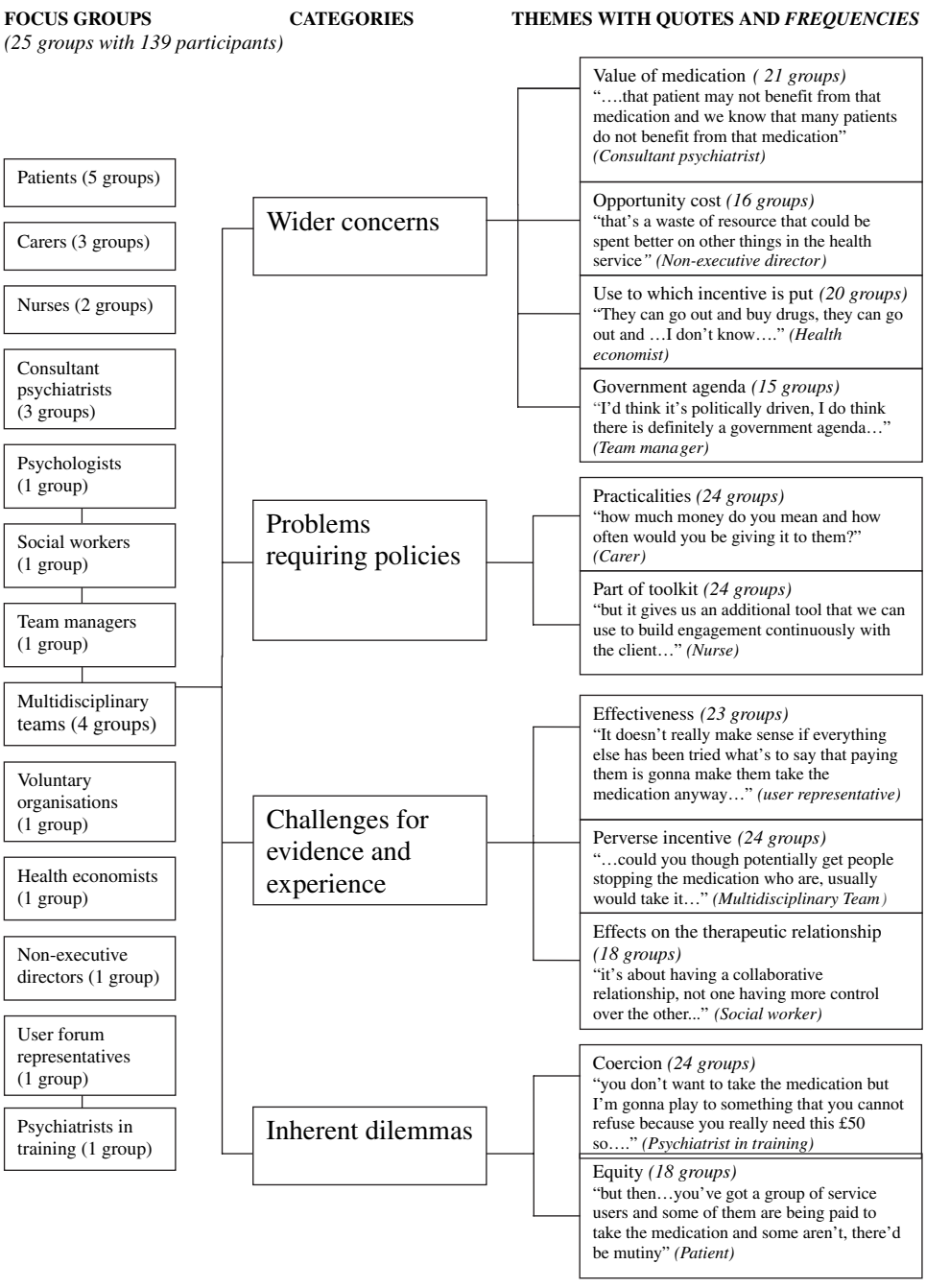


Figure 1 Focus groups, categories, emerging themes and illustrating quotes.

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alternative services. While the term 'government' directly featured in 15 groups, only one participant supposed an interest of pharmaceutical companies as a potential driver.

These themes were categorised as wider concerns because the question of financial incentives was specifically on cases in which medication was supposed to be effective, and would be irrelevant if medication was deemed unhelpful for a given patient. The question of where the money for the incentives would come from applies to any new healthcare intervention that needs funding. The concerns about what patients might spend the money on is addressed by legislation and civil rights, according to which people with severe mental illness have the same entitlement as anyone else to spend their money on what they see fit. Finally, the speculation on political drivers behind the idea of financial incentives is separate from the clinical practice of whether it should be considered by a clinician for a given patient. All these concerns highlight a difficulty in evaluating incentive schemes: separation of the evaluation of the incentive scheme from evaluation of the context in which it is used and from evaluation of the treatment or behaviour being incentivised is very difficult in practice, even if the distinctions are clear analytically.

Problems requiring policies

Two major themes addressed issues that would require further clarification by precise policies.

Participants frequently raised questions about the practicalities of offering financial incentives and the feasibility of such a practice. They wondered how the incentives would be administered, how receiving money would affect benefit schemes, and over what period of time the incentives should be used.

If the financial incentives were seen as a reasonable option and 'part of a (clinician's) tool kit', there was still an emphasis that safeguards have to be in place to ensure that it was used only as a 'last resort' when all other efforts had failed. It should not become an 'easy option'. There was a consensus that every attempt should be made to understand why a patient had stopped taking medication so that options for alternative interventions could be explored.

These problems suggest that the acceptability of an incentive scheme can be improved by improving its design. They also underline the disquiet that incentive schemes produce, even when the context and design of such schemes are fully clarified. A pragmatic objection to an incentive scheme is possibly easier to articulate than a moral argument.

Challenges for evidence and experience

Three themes concerned issues that may, at least in theory, receive some clarification through evidence from research and clinical experience. While some of the issues may be addressed in conventional trials, others may be more difficult to study.

Participants frequently wondered whether the practice would work and indeed lead to higher medication adherence. Many participants welcomed the idea of further research to establish the effectiveness of the scheme and stated that this was the most important factor in determining the acceptability of offering financial incentives. Others dismissed this as a non-starter and were opposed regardless of the potential effectiveness, arguing that they could not see how it would work in practice or that it was wrong for reasons captured in other themes of the analysis.

Similarly, concerns were raised that offering financial incentives to those who were non-adherent could have a negative impact on those who were medication-adherent, with the potential of encouraging non-adherence in order to obtain money. Participants with less direct and personal experience of community mental healthcare of psychotic disorders, either as patients or clinicians, were particularly likely to argue that financial incentives might encourage false reporting of ill health, and conversely a reluctance to report side effects and negative consequences of taking medication.

Clinicians in particular wondered whether offering financial incentives might affect the therapeutic relationship and undermine a collaborative process with the patient. In addition, there was wide concern about whether being offered incentives to take medication would lead to a more negative attitude towards medication, instead of a more positive one due to experiences with helpful medication effects.

Inherent dilemmas

This fourth category contains two themes that appear inherently linked with offering financial incentives to achieve medication adherence in patients with psychotic disorders and cannot be clarified through policies or research. Rather they articulate concerns of moral principle, which are not evidence-dependent.

Financial incentives were seen as a 'powerful tool' in enabling behavioural change. Some stakeholders felt 'uncomfortable' at the thought of using money in therapeutic practice, particularly as it targeted the poor and could be used to influence the decisions of vulnerable people. Some participants suggested that the use of incentives other than money would feel more comfortable, with vouchers being a popular alternative. A core issue was whether the introduction of money would motivate patients to make decisions that may go against their beliefs on what was right for them. It was felt that patients might continue to take the medication despite intolerable side effects. Some participants, however, saw money for medication as more of a reward or 'compensation' for having to put up with side effects, while others emphasised that service users still had a choice over whether to take the money and therefore take the medication. This led to the question of who would be responsible for the patient's decision in such a situation and for potential negative long-term effects of the medication. In this context financial incentives were potentially coercive. Views were inconsistent as to whether such a form of 'coercion' would be preferable to formal methods of compulsory treatment using the Mental Health Act. Mainly clinicians argued that in practice many other methods of covert coercion and indirect material incentives, such as invitations to lunch or help with filling in forms to get benefits, are routinely used to encourage medication and do not draw criticism.

Finally, the question of whether it is fair to offer some patients money to take their medication while others do it without receiving money was raised and frequently seen as a matter of principle.

DISCUSSION

The study illustrates what issues are likely to be raised when financial incentives to achieve medication adherence in non-adherent patients with psychotic disorders are discussed. Each stakeholder group covered most of the same discussion threads, albeit with different emphasis and arguments, but there were no clear differences between groups. The concerns expressed in the 11 themes need to be addressed whenever a wider application of the practice is considered. The relevance of these themes is twofold. First, they arise prior to any consideration of the

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evidence of effectiveness of either treatment or incentives for treatment. Therefore, they shape the perception and argument around the topic of incentives in an important way. They are also broadly consistent with academic arguments about incentives. One methodological question arising in our study was whether we were 'promoting' the use of incentives, or whether our prior attitudes to antipsychotic drug therapy were relevant in framing and analysing the issues under investigation. Obviously, a degree of reflexivity is necessary here. But the very concern raised about whether we are in some way biased or whether our framing prejudged the discussion is itself something that was discussed in the groups, and underscores the way in which prior moral attitudes frame the debate in ways that seem rather insensitive to evidence, even where evidence should be relevant.

Strengths of the study are that very different stakeholder groups were included, saturation was reached, and the results appear plausible as a criterion of validity. Weaknesses are the general limitations of focus group methodology and the fact that very few participants had any experience with using financial incentives, so that most concerns had a speculative nature.

The debate in the groups raised wider issues and specific concerns, which to some extent reflect a suspicion that offering financial incentives might not only be a desperate attempt by clinicians to help patients in whom all other means have failed, but also that there are improper motives and even a government agenda behind it. One can only speculate whether this is influenced by the public nature of the NHS, the way that the NHS has been run using top-down initiatives, and the general politicising of health service issues in the UK. Aside from health system-specific issues, it was not clear how far participants attitudes were driven primarily by concern for the individual patient's well-being and respect for their autonomy, and how far they were shaped by a concern for social justice and equity in ways better captured by a public health model of the use of incentives.[14] Having said that, most of the concerns identified relate to concerns on individual behaviours and attitudes, and for between-patient considerations of fairness.

Whether offering financial incentives is an acceptable option or not is an issue for an ethical debate, and the findings of this study can inform such a debate. Since most of the ethical arguments raised seem to relate most to a clinical frame of reference concerned with the individual patient, a normative model drawn from medical ethics may best capture the nature of these concerns. A standard framework for describing such concerns is that of Beauchamp and Childress,[15] who suggested four ethical principles guiding the consideration of healthcare interventions: autonomy, beneficence, non-maleficence and justice.

Each of these principles has been addressed by the results. The autonomy of the patient might be affected through a coercive effect of financial incentives with unclear responsibilities for potentially harmful medication effects, especially in the long term. While it may be argued that the model of coercion implied in the respondents' discussions was inchoate and arguably quite imperfect from a philosophical point of view, notions of coercion were frequently invoked and appeared highly salient.

Beneficence overlaps with the issue of effectiveness, but is also linked to the frequently discussed question of whether offering financial incentives is in the interest of the individual patient or the public at large. Ethically, only the former might be seen as a justification to implement the practice in a voluntary treatment setting. In addition, capacity to make the decision and provide informed consent would be required.

Several aspects concerned non-maleficence, referring to potential harm. This may affect patients on such a scheme through the withholding of time-consuming alternative methods, more complicated relationships with their clinicians, more negative attitudes towards medication, or the harmful use of the money for drugs. It may also affect other patients who might become non-adherent to be eligible for financial incentives.

The issue of justice was directly mentioned as some participants found it unfair that some patients received money to take medication and others did not. Such a position may be challenged by arguing that resources for health interventions need to be distributed following the needs of the individual concerned.

The four-principles approach is only one approach to thinking about the ethics of medical treatment, and of incentives, but it has the virtues of simplicity and clarity. Although frequently criticised for being simplistic, it does help make sense of the 'ordinary ethics' recorded in the focus group discussions.[16]

Relevant stakeholder groups expressed concerns about using financial incentives to achieve medication adherence in patients with psychotic disorders. If the practice is to be used more widely despite these concerns, financial incentives should be regarded as an option for a clinician and patient in an individual case, rather than be implemented following a general guideline. The study has clearly shown why offering financial incentives to achieve medication adherence will remain a controversial subject. While the ethical decision may depend on various factors, including the central question as to whose interest is being served, some of the concerns can be addressed by precise policies with appropriate safeguards, and others might be clarified in further research. Our analysis here is not intended to be a full ethical analysis of the issues, but rather to identify which issues are salient in stakeholders' appraisals of the use of incentives to promote medication adherence, and to examine how these arguments are used to shape their understanding of the use of incentives. The 'lay ethical theories' of our respondents leave open difficult questions about the nature of coercion and the distinctions between coercion, inducement, persuasion and rational response to behavioural and cognitive biases. It is possible, for instance, that an a priori concern with coercion in psychiatric practice disposes our respondents to identify new behavioural interventions as presumptively coercive. This would not mean that incentives are coercive on the best theoretical analysis of coercion, but it would mean that stakeholders are more likely to perceive, interpret and evaluate incentives using a 'coercion frame' rather than a 'rational choice frame'. Since autonomy in the thin sense of the capacity to make unforced decisions made in light of the person's own preferences, and in the thick sense of being able to live in light of a coherent, reflectively endorsed set of values, is at the heart of psychiatry, it should not surprise us that a complex negotiation over what it requires takes place when incentives are proposed.

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Competing interests SP, MF and RA are members of a research team that has been granted funding by the NIHR Health Technology Assessment Programme to conduct a randomised controlled trial on the effectiveness of financial incentives to improve adherence to anti-psychotic maintenance medication in non-adherent patients. Beyond this, there are no direct conflicts of interest relating to any authors and the contents of this work.

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Contributors SP, JS, AB, SM, JL, MF and RA were all members of the research team from the beginning of the study to the final analysis and involved in the analysis and discussion of the findings. JS, AB, SM and JL acted as facilitators and co-facilitators of the focus groups. JS, AB and SM coded the data. In the discussion, MF contributed particularly on practical aspects and RA on ethical issues. SP led the whole study and analysis, and is the guarantor for the study.

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