**Just Festival**

**A SPOONFUL OF MONEY: INCENTIVISING HEALTHCARE**

co-facilitators: **Waverley Care**

St John’s Church hall

Princes Street, Edinburgh

14 August 2014

*Where is the line between personal responsibility and public health? NHS Tayside gives incentives to encourage people with hepatitis C into treatment. Is this a good use of NHS resources for the greater good or an undermining of personal responsibility? An exploration of the ethical issues associated with offering financial rewards in healthcare.*

**Chair**: **Sheena Macdonald** (journalist)

**Panellists**: **Dr John F Dillon**

(consultant hepatologist and gastroenterologist,

NHS Tayside)

**Kenneth Boyd** (medical ethicist)

**Marion Chatterley** of Waverley Care introduced the event.

**Sheena McDonald**, a keen supporter of Waverley Care, opened the questioning on the unique project being undertaken by NHS Tayside.

**JD** – treats hepatitis C patients on a daily basis, and described the blood-borne virus, which is carried by 1% of people in Scotland and can slowly lead to cirrhosis or cancer of the liver. It tends to be spread by the sharing of needles, now mainly through recreational drug and steroid use. Previously, it was also spread through healthcare interventions by contaminated instruments.

Scotland has a world-leading action plan to prevent liver failure and liver cancer, and the number of patients affected is now flatlining, as predicted. Dr Natasha Martin made a mathematical model for how hep C spreads among the drug-using population. Assuming a 20%-40% prevalence among that population in Scotland, and if just 10 to 20/1000 are treated, then prevalence can be reduced to under 5%. Eventually, Scotland could eradicate hep C.

It was assumed to be impossible to treat drug users, but heroin users in Tayside are engaging with this programme.

JD had heard about encouragements to pregnant women to stop smoking, using food vouchers, so the idea was taken to a needle exchange in Dundee: patients who agreed to treatment would be given £5 Asda vouchers (not to be used for cigarettes or alcohol), along with protein supplements. Patients were not asked to change their drug use.

There are currently 43 patients involved, of whom 14 have completed the course and 12 have been cured. One initially agreed but then committed a crime and was apprehended, and was treated in prison. The number of DNAs (did not attend) was low. It is still early days in the project, but there is some initial evidence of crime and drug use rates among the group going down.

Essentially, JD wants to stop the spread of hep C, and is paying patients to help him.

**KB** – made the point that money can also be used as a disincentive: taxation on alcohol and tobacco. In the form of salary, it is used to pay doctors to get people to change their behaviour.

Incentive schemes vary in their success. Are they enough to change behaviour? Can they be controlled and monitored? They can be less effective if the goals are more long-term and complex. They may not be justified if the goal is simply to change behaviour, but here the goal is to eradicate hepatitis C.

The principle of autonomy includes responsibility with respect to others. In this case, despite having mental capacity, patients have already gone against medical advice in their drug use. Are we going against their autonomy or possibly undermining the therapeutic relationship?

The carrot is more ethical than the stick. It is a matter of helping people to do what is in their best interests and what they would do if they reflected more on it. Is the project affecting people’s autonomy? Is giving people a nudge in this way bribery or coercion?

The principle of doing more good than harm should always be remembered.

**JD** – As regards the treatment, the effect of the interferon injections is not pleasant – the effect is akin to having flu. Patients are told the treatment is potentially life threatening, albeit it is in their long-term interest.

**KB** – As long as there is openness, and patients are told full information.

**JD** – About 40 people were approached but did not agree to proceed. Patients’ idea of ‘long-term’ might be rather short-term by more general standards. The patients tend to be young, and their hepatitis condition is not yet serious. Drug use poses the biggest short-term risk – but patients still appreciate the long-term benefit point regarding the treatment.

**KB** – Is the project fair? Public funds are being used for certain hepatitis patients only. Are the incentives there to address health inequalities? Are those involved vulnerable individuals, or are they adults able to make decisions? Are personal cultural/behavioural issues being turned into a health issue? Does being paid in fact make people less dependent?

***From audience***: Many hep C patients do not get these vouchers, as they are not leading chaotic lives.

**JD** – Most hep C patients are in a stable phase of life and desire to be treated; the group in Tayside are being treated for the sake of the general population, not for the patients themselves. The goal is to prevent hep C being passed on to others. The question is whether the vouchers are effective.

***From audience***: Are patients still paid if they become reinfected?

**JD** – Testing at the needle exchange shows that only 8 / 1000 have been reinfected, thanks to clean needles etc. and hence reduced risk – ‘safer drug abuse’. Perhaps the unpleasantness of the treatment is also a factor.

Treating hep C is most cost-effective for drug users and for those on the brink of liver failure. The £5 voucher should be compared with the £400 price of the new tablets, which should cure 90% of cases. The new drugs will cost £60,000 per person, but treating one person offers prevention for 30 people.

Welfare costs are not taken into account.

Behaviour change could make the project a positive experiment, e.g. one patient has come off heroin, secured housing and saved up the Asda vouchers – and has recovered despite a relapse. Health inequalities are indeed being addressed.

***From audience***: Might a drug user’s friend, possibly injecting together, take deliberate risks in order to obtain vouchers?

**JD** – Probably not. The rewards are small, with a maximum of £120 in vouchers. (But is that a lot of money for them?)

***From audience***: How do the patients respond when their treatment is over and the vouchers stop?

**JD** – Patients still come in for coffee, to have chats, get advice, etc. This is part of the rehabilitation pathway.

The project has had some publicity, and the Scottish Government has been supportive. £2m of investment has been made. In BBC radio interviews, for example, the greater good has been emphasised. There has not been a particular negative ‘*Daily Mail*’-type response so far.

It will take around 5 to 10 years for hep C prevalence to decrease in Tayside. The rest of Scotland is effectively a control population.

***From audience***: Could the money be used for anything more worthwhile?

**KB** – It is the politicians who take the decisions. It is a good thing that doctors are advocates for their patients, and they should make the arguments so that politicians can make informed judgments.

***From audience***: More investment should be made to address inequalities, focusing on people who have been disadvantaged from the start of life – despite individual autonomy.

**KB** – Medicine has a bias towards cure; prevention has longer-term, less immediately tangible outcomes. Many acute interventions would not be needed now had there been more prevention in the past.

Autonomy should mean personal responsibility, but there is a tension between autonomy and choice – ‘I should do whatever I want.’ People’s decisions do affect the rest of society, so a balance is needed.

**SM** – Indeed, there are well-off people who drink too much alcohol and develop cirrhosis. Is taxation on alcohol really effective?

**KB** – It does seem to work in Norway.

**MD** – On alcohol pricing, there has been a 25p / unit rise in price lately, and admissions due to liver failure have fallen since the start of the financial crisis, as people can afford less alcohol.

***From audience***: What about the expectation value and the variance of the financial reward per person?

**JD** – The £120 of vouchers is a maximum. Most patients get all the vouchers, so the average amount taken is around £105.

Funding for the project, which has not been done anywhere else in the world, is from two pharmaceuticals companies, NHS Tayside and the Scottish Government. The cost of the drugs is a limiting factor.

Whereas it is known that around 40% of those in the group in Dundee are infected, there are also plenty of people in the general population coming forward for treatment.

The trial has gone through the usual processes, including consideration before an ethics committee.

***From audience***: Many people are being treated and not paid. Perhaps the project will be repeated elsewhere.

**KB** – The payments are more ethically acceptable if this is being done as a project.

**JD** – It will be up to politicians whether it is acceptable in the future.

***From audience***: What about providing treatment in the home?

**JD** – The project has been conducted in the needle exchange, which is in fact close to where the people live, some of them having no fixed abode in any case.

***From audience***: Are there plans to change the incentives? The protein drinks are apparently popular – are they in fact the leading motivation, rather than the vouchers?

**JD** – More services were offered at the start. A telephone helpline was not used much, nor was a methadone service; it was the protein drinks and the vouchers that were taken up most.

***From audience***: What about fairness with respect to those in rural areas?

**JD** – It could indeed be said to be unfair for some, but the drug users concerned are concentrated in the main urban areas as we would expect. Most of those in other areas will tend to access healthcare in a more conventional way.

***From audience***: Are the relationships formed with staff a positive and important unintended consequence of the project?

**JD** – Yes. The project has been fortunate to have good staff. The research nurses have been praised: they are conversational, caring and interested. Is that, in fact, an incentive to undergo the treatment?

**KB** – Such factors can be a problem for assessing such experiments. There might be a brilliant nurse involved in a project – but the same might not always be the case outwith the project. The human factor is indeed important. KB discussed examples concerning the Liverpool care pathway and permission for retention of babies’ brains post mortem, and gave a reminder that the principal aims are said to be to care for the sick and comfort the dying.

**JD** – It is possible to assess the value of the scheme, but if there are personality-driven incentives, they must be maintained.

**SM** – Can the vouchers still be effective without the human element?

**JD** – The three research nurses are all good, hence it is a problem to prove the success of the actual incentives independently.

With the regular weekly personal contact, perhaps the structure to people’s lives has been important in itself – hence the telephone helpline was not so successful.

***From audience***: The project is long term, and it is for traditional drug users, but what about new drug users and new drugs?

**JD** – All users at the needle exchange are assisted, so the project therefore mainly covers opiate users, and steroid users to some extent – e.g. bodybuilders, who are more health-minded.

At the end of the five-year pilot, the number of people cured and reinfected, compared with the rest of Scotland, will be considered in deciding whether it can be used to deliver more widely. JD hopes to prove that the model works, leading to lower prevalence of hep C and preventing liver failure.

***From audience***: As well as lowering prevalence, is the aim also to improve nutrition?

**JD** – Provision of protein drinks is standard, to prevent weight loss, and they work out at 1p / dose.

**KB** – People within the group therefore have an advantage.

**JD** – The extra nutrition will not serve as a cure on its own. People are underweight, partly because of the drugs and also as interferon can lead to a 10% weight loss, so the protein supplement is to compensate.

Patients do drink the protein drink – it does have a street value, and might sometimes be shared, but is apparently not sold on very often, judging from anecdotal evidence.

***From audience***: What about TB? 6 million people have been treated, using incentives, in San Francisco and New York, for example. What about Scotland? And could the Tayside project also be adopted in Lothian, for instance?

**JD** – It used to be a stick, rather than carrot, that was used for TB.

***From audience***: In some African countries, TB patients could be locked up in hospital for six months.

**JD** – Treatment of TB also focuses on the benefit to society.

***From audience***: Following this project, might general expectations change? Might people start to expect payments?

**KB** – That is a matter of culture. Note that incentivisation is more effective in the US, because there are more barriers to healthcare there compared with the UK NHS, where there is more of a notion of solidarity. Here, blood donation is a gift; in the US, there are incentives.

**JD** – The protein supplement is perhaps more valuable, and acceptable.

The NHS is being flexible with regard to the programme, and there has been more flexibility around hepatitis C treatment because of its more recent discovery compared with TB, where there are more entrenched attitudes.

**SM** – Perhaps the costs of the new treatments will go down.

**JD** – There will be competition. The new drugs are simple to administer and could become more widely available. Perhaps the new hep C treatments could be taken under supervision like methadone.

***From Waverley Care representative***: Perhaps incentives could be used for others with more chaotic lifestyles who struggle to seek treatment autonomously – referring to the Milestone residential care unit.

**JD** has seen a problem and believes that it could be solved during his career. The challenge is to deliver in places where help would be most effective.

**KB** – Ethics is about weighing things up. KB supports the project.

*When asked by SD, the audience expressed unanimous approval for the incentives discussed.*

*Summary by Robert Arnott*