My name is Llew Lewis. I am a consultant psychiatrist working in general adult psychiatry in community services in Southend. I am also the local lead for the so-called Maintaining Adherence Programme, or MAP for short, which is a model of care we have been piloting over the last three years in Southend, implementing it and evaluating it, so I am going to be using the opportunity today to share with you a little bit about what the model looks like but also some of the encouraging interim results that we have got.

We have called the talk Achieving positive outcomes through innovation in community health services, but before going into detail about what the model looks like, I thought I would just put some context around the environment we found ourselves in over the last three years and the challenges that we are facing in health care. At the risk of stating the obvious, lots of you will know about the so-called ‘Nicholson Challenge’ to save in the region of £20 billion in the NHS over the next few years. We are in the middle of this process with 4 per cent efficiencies being required of us year upon year, but despite those financial challenges, we also at the very least have to try and maintain the quality of our services and the safety of our services and, if aspirational, try and improve the quality through driving up productivity and efficiencies.

None of us will not have heard about the problems that happened up in Mid-Staffordshire, which resulted in the Francis report with over 200 recommendations to NHS organisations to improve our game, so this paints the picture of the environment that we are working in at the moment. At the same time, for those of us who are working in mental health, we face significant challenges in treating the psychosis. The treatment is multi-factorial; it’s complex.

Professor Sir Robin Murray chaired the Schizophrenia Commission and produced his document in November 2012 and entitled it The abandoned illness. I suppose that sums up the experiences that service users and carers and perhaps providers were sharing with the commission about the state of treatment for our patients. All of us will be aware that over the last 10 years there have been significant reductions in the availability of mental health beds and only recently in the newspapers last week we heard about the increased use of Community Treatment Orders or the Mental Health Act to treat people in because of the lack of availability of beds.

In his document and in lots of other places it is recorded that patients with Schizophrenia have problems with medication adherence and the non-adherence to treatment increases risks significantly for psychiatric relapse and admission to hospital, with all its attendant consequences to the individual in terms of lost opportunities for social functioning, occupational functioning, relationship functioning, not to mention the demands that are placed on carers and families sometimes on plugging the gaps in services which they might perceive are not there. Then, of course, you have got to bear in mind the economic costs. It is expensive to be admitted into a ward. The admissions often take a long time and, as was drawn out in that Schizophrenia Commission Report, there is a massive pressure on resources; a perceived lack of staff time; staff complain of the lack of availability of structured programmes and little or no support to wards.

So that’s where we are at but it is not ‘new’ news. In Germany about 10 years ago an innovative psychiatrist called Dr Werner Kiβling identified the same problems and he recognised that about 50 per cent of patients who have an acute episode of bi-polar or schizophrenic relapse are admitted to hospital again within a year. Even with conservative estimates of adherence, above 45 per cent of our patients are not adhering to treatment. So he hypothesised that if you were able to develop a bespoke adherence model to address this problem, you may be able to reduce the demand on services. There is evidence that the psycho-education approaches and wellbeing approaches help
patients to manage their own illnesses better; perhaps spot early warning signs of relapse and learn how to access services more quickly.

What he did was a mirror image study, looking at the costs associated with patients in the 18 months before they went on a programme compared to the costs after they were on the programme. He wrote this work up and what he was able to demonstrate was that for the patients who completed the programme, they were much less likely to be admitted to hospital. He was able to demonstrate a 70 per cent reduction in bed days which amounted to in the region of €5,000 per patient per year. He published this work and Janssen, under the umbrella of Johnson & Johnson, a pharmaceutical company, became interested in the work and wanted to see whether a model that was that effective in the German healthcare economy could be piloted in the NHS.

So that really began the conversation between our two organisations and we were interested in this question of whether we could pilot the same model in the NHS. We wanted to partner with Janssen under a joint working agreement and it is probably worth mentioning at this point it had nothing to do with any of the drugs that they make. Many of you will know that Janssen makes haloperidol and haloperidone and various other drugs, but this was not anything to do with the working agreement that we had with them. Their objective was to help us develop a new service model, unrelated to the other area of their business.

We wanted to translate and modify this adherence model to the UK context, as I have said, and to test it within our organisation. SEPT stands for South Essex Partnership Trust. We are an integrated healthcare organisation that delivers mental health services and community services in a number of areas in South Essex, Bedford and Luton. We have about 3,000 staff, 200 locations and I just work in a small part of that in Southend where we decided to evaluate the clinical and economic benefits and outcomes of this model.

Now you might ask, why would we consider doing this? And I suppose, despite all the advances that emerged under the national service framework in which we saw the development of services to try and prevent admissions to hospital by early intervention; the search of outreach for the other end of the spectrum where patients are difficult to engage; crisis in home treatment teams. We have also had amendments to the Mental Health Act in 2007 with Community Treatment Orders. All of these new systems in place are essentially to try to improve care for patients. Despite all of that and very advanced psycho-pharmacology, patients still relapse. That was compelling for us. We wanted to improve the quality of care and outcomes for this particular group of patients, schizophrenia, schizo-effective disorder, bi-polar disorder and to reduce the overall resource usage, in particular occupied bed days in our Trust, in this climate of radical financial pressures that I have been drawing out.

So what does this model provide? In the first instance we have a dedicated adherence team. I offer five sessions of my time as the consultant psychiatrist to the team. We have one band seven nurse who is the operational lead for the team; two band six nurses and two part-time occupational therapists. We deliver interventions in a so-called ‘recovery lounge’. It is worth making the point that in Germany they incentivise patients to take part in the programme by paying them, but they also believed in soft incentives to create a nice environment for patients to come to where we could serve good coffee and customer care and make them feel special about being in a programme to try and keep them in the programme. So the recovery lounge is something which after three years we managed to get. We did have it at the inception of the project but we have a much nicer place now that is on street level; it is separate from the community mental health team; it has great furniture; it has great coffee and we have all been trained in customer care – how to welcome patients into the programme to try and retain them in
the programme. In Germany, Werner Kißling spoke about the sort of Lufthansa first class lounge. It’s that sort of idea that we have tried to implement in Southend.

What we do over the course of the programme is assessment of baseline using a 16 item checklist that is not a validated measure, but it is essentially all the known risk factors that are associated with non-adherence. It covers things like severity of illness; patients being on medication that has intolerable side effects; carer support; lack of insight – various other domains. We capture all that in the information at baseline so that we can develop a bespoke care plan for the patient over the course of their engagement with the programme. We do that questionnaire every three months. Embedded in that questionnaire is a validated medication adherence rating scale and essentially it is a way to capture attitudes, beliefs and behaviours around medication adherence. If you score better than 6 out of 10 you are more likely to be adhering.

We have used these data over the course of the programme as secondary outcome measures but also as clinical tools for the team so that they know which areas they need to address when meeting with patients. The key intervention however is structured and in-depth psycho-education. We have 11 sessions of psycho-education that we give to people with Schizophrenia over a three-month period. They have the groups once a week in the recovery lounge. It is facilitated by two MAP workers. We have all been trained in facilitation of psycho-education groups. The content is in manuals that the patients can use within session or between sessions for homework. We are also supported by audio-visual support tools that are built into an application in iPad so the team can press a button on the screen and pull up all the videos that have been filmed and patients’ stories that we use as an adjunct to ordinary teaching methods like flip charts and white boards. Topics that we cover include diagnosis of Schizophrenia; causes; symptoms. We go into quite a lot of detail around the dopamine hypothesis and the stress diathesis model.

When we saw the content of the material at the outset some of us were a little bit sceptical about whether a patient with Schizophrenia would sit through three months of psycho-education. But it must be the brilliance of our skills that we have developed and the good coffee that has attracted people to stay in the programme! We also cover early warning signs of relapse, crisis planning, recovery, drugs and alcohol, sexuality and relationships.

For the bi-polar programme, we use an evidence-based intervention which is based on cognitive behavioural approaches. We teach patients about medication for bi-polar disorder; how to spot early warning signs of depressive or manic relapse and then what to do in a crisis. We also cover communication in families and the intervention has been evaluated in one-to-one sessions and been shown to reduce helplessness in patients who are confronted with very extreme moods that they may experience.

We do the same thing for families and carers because the evidence shows that if you have a two-pronged approach, the patients do better if family are able to identify early warning signs because often the patients may not. So patients do better if you give the approach to their families and we have just started recruiting volunteers to do peer psycho-education. These are patients who have completed the programme, gone through all our processes so that they can volunteer and we are starting that programme this year.

Wrapped around the psycho-education are wellbeing activities. These are activities which allow us to have informal interactions with patients to identify if someone is starting to talk about wanting to come off their medication, or if they look like they are having early warning signs we use those activities to identify it. We have got coffee and culture groups; walk-jog groups. We have got some psycho-education around healthy diet. The wellbeing activities also allow us, if we think patients are not going to be socialised into a
group setting easily, we use the wellbeing activities to identify levels of functioning so that we can stream patients into appropriate groups. We do not want to mix up very high functioning patients with low functioning patients because it takes a lot of skill to pitch the information at the right level.

We have an approach to shared decision-making. We have all been trained in shared decision-making approaches so we enter into a collaborative partnership with patients, giving them high quality information using the Choice and Medication website. If a decision needs to be made about medication, we make an appointment specifically to go through all the pros and cons of different treatment options. On the Choice and Medication website there are lots of handy comparative charts between different anti-psychotics and anticonvulsants and anti-depressants. By giving them that information, we help them to make a decision which hopefully they will feel they have made and that is associated with better adherence.

For patients with problems organising themselves or memory problems we have telephone texts reminder services. We remind the patients of when their appointment is with the depot clinic, for example. They can have oral medication reminders up to three times a day through an SMS or through a voice. We also remind them about when their appointments are so we have quite good attendance.

The other approach we have taken is, because the assessment at three months is a very structured one and the team do that, I do not see patients routinely. It is only if the team feels that they need an appointment, so I am only focusing on people that are in crisis or when my very expensive resource is best placed so I can respond very quickly to people who need to see me because I have capacity in my diary.

So what we did was similar to Dr Werner Kißling. We recruited patients into the programme and looked at a number of data but they may now be measurable with in-patient bed days. This is interim data on 63 patients but we have other data on 93 patients in total who were completers of the programme. The 58 per cent reduction we see in the in-patient bed days is 50 days prior to being in the programme versus 21 days after being in the programme. In Germany, as I mentioned earlier, they got about 70 per cent and it may be that they switched a lot more patients in Germany onto depot anti-psychotic medication. In our cohort, when we were looking to recruit patients into the programme, the patients on depot anti-psychotics were too well to be in the programme. Patients on clozapine had also been out of hospital for too long. We only included people in the programme who had had an admission to hospital in the last 18 months or who had been very heavy users of services so we think that is quite a good result, even though we took out some of the effect that might have been seen in Germany through the switching of patients to depots.

I spoke a little bit about the secondary outcome measures: the MARS (medication adherence rating scale). Over time we saw a statistically significant improvement in the score from 5 which indicates in this cohort that they were more at risk of non-adhering, to 8 after the programme. Actually when we looked at the data, the patients made their improvements in the first three to six months. The improvements after that time were not very significant, which indicates that the main intervention is the psycho-education. Similarly, the risk score out of 16 – we have not put it out of 16 on the screen but the total score is 16 – we went from 10.4 baseline, so they had 10 risks associated with non-adherence, down to six over the course of the programme. We were happy with that. Those scores were going in the right direction and could be thought of together with the main outcome data.

We did qualitative surveys of patients after each group and at three months, six months and 12 months, and out of the respondents – and there were 50 out of 63 respondents in this data – more than 80 per cent of them felt involved in decisions about their
treatment and the other encouraging one was that 98 per cent of them would recommend the service to a friend. We also got some qualitative comments from patients and I have just included two there that you can read.

So the question is what are we going to do with this model going forward? Well we are still in discussions and working with Janssen Healthcare Innovations to try and roll out version 2. We are renaming the programme ‘Care for Today’ and we would like to pilot it in another community mental health team in different parts of our Trust. We would like to integrate it better with community mental health services. In addition we want to pilot an electronic patient management system which will hopefully make us more efficient. The reminder service that were using until now was commissioned, paid for through an external company but we want to bring it all into our patient management so you can send patients SMSs, texts, and there is also a patient and carer education portal that they can access remotely through the Internet. We can make the resources that are in the booklets available to them and their carers through that portal.

We are also developing some physical health modules just touching again on some of the presentations that happened earlier regarding the 20 year mortality risks that our patients with SMI face compared to other people.

So that is our model and I hope you found it interesting.

Thank you for your time.