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The video can be viewed here.

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So I'm Simon Chu; I am a Research Fellow at Ashworth Research Centre based in Ashworth Hospital part of Mersey Care NHS Trust and I am also in the School of Psychology at the University of Central Lancashire.

I've been asked to come here today to talk to you about my personal experiences of apply to RfPB for funding and the process through which we developed the proposal that ultimately got funded.

Having listened to Professor Armstrong's presentation I think a lot of my experiences pretty closely match what Professor Armstrong was talking about in terms of the ethos of the RfPB and the process that's important in applying for the things.

So briefly what I'll do in the kind of 15 to 20 minutes is talk to you about why I'm talking to you about this. Talk to you very briefly about the RfPB project that was funded a couple of years ago. Talk to you at some length about the development journey through which that project went through and the different turns and twists that were involved in getting it from the inception of the idea to the final project that was proposed and submitted and a little bit about the things that I think helped us get that project funded.

So I hasten to add that whatever I do say about what I think helped us get funded is just my own personal opinion about what I thought helped us get funded and it is not in any way reflective of the NHIR view or the RfPB view or even the RDS view about things that help you get funded; It's just what I think. You might think that what I think is not particularly useful but we got there so it might be helpful.

So those are the things I'll cover in the next 15 to 20 minutes or so.

First of all a little bit about me; I am a Psychologist by training; I read a PhD in Psychology far too long ago than I care to remember. Mainly an Academic Psychologist; I've has a teaching post at Liverpool and currently at UCLAN.

My research interests are in main stream academic psychology; so I've done a lot of work in human memory, cognitive processing, face processing, evolution psychology and mate-choice attractiveness; it's all kind of very standard main stream cognition and psychological research that's academic and actually not particularly implied in very many ways.

I mention that because so up until 2013 I was not involved in Health Research in any way whatsoever. Why that's important it's something that I'll come on to later on.

So it's only until relatively recently that I've been involved in Heath Research because since 2013 I have been appointed to as a Research Fellowship post at Ashworth Research Centre, which is a Mental Health Hospital based in Ormskirk.

Since then I have been heavily involved in Mental Health Research; so things to do with Service Delivery; Mental Health Nursing, Patient Experience in long-term Mental Health care and so for the past few years I have been involved more and more in Health Research talking to clinical staff, psychiatrists, clinical psychologists, frontline ward staff; I'm talking about their experiences in dealing with patients and delivering care in the NHS.

That's really where this project came from; the project that we got funded through RfPB is a feasibility study of glycopyrrolate in comparison to hyoscine hydrobromide and placebo in the treatment of hypersalivation induced by clozapine.

What does all that mean; the GOTHIC1 trial; the GOTHIC1 acronym does come out of that title somewhere; we had to really grapple with the letters to try and make it GOTHIC1 but we really wanted to call it GOTHIC1.

So the GOTHIC1 trial I'll tell you briefly about what it is that the trial does and why we thought it was a really important question to answer. The GOTHIC1 trial is really addressing one of the side effects of a medication called clozapine. If you don't know anything about Mental Health care then clozapine might be something that's kind of alien to you but clozapine is a medication that is prescribed to treat treatment resistant

schizophrenia. So patients who suffer from schizophrenia and have diagnoses of schizophrenia are often prescribed antipsychotic medications and only some of them work some of the time.

A proportion of patients who are prescribed antipsychotic medications don't respond to them and when they don't respond they get prescribed the second one and a third one and they go through a series of different medications until they find something that works.

The very last line of defence is a medication called clozapine and it's the very last one they try because the side effect burden with clozapine is really very, very heavy; it can be fatal. So whenever a patient is prescribed clozapine initially they go through a series of weekly blood tests in order to check that they haven't developed a blood disorder while taking clozapine. In most cases it is a lifetime prescription and they need regular blood tests for the whole time they're on clozapine.

Even though it has got a very heavy side effect burden it's a very important medication because it's quite effective and there is literally nothing else that the patients can turn to.

So whenever someone starts on clozapine; whatever patient begins clozapine treatment it's very important that we keep them on clozapine because there's literally nothing else to try.

The problem is that the side effect burden of clozapine is really very, very heavy – weight gain, sedation and the most unpleasant side effect of clozapine is the fact that they drool a lot. Patients on clozapine tend to hyper salivate.

Now to you and me hyper salivation doesn't sound like a very big deal. Producing excess saliva you can just swallow it; why would it be a problem. But for a patient on clozapine he's hyper salivating it is a very socially debilitating side effect; it's terrible. Whenever you're talking to somebody you're spitting at them; whenever you're having a meal you're drooling down your face; whenever you fall asleep during the day which is another side effect of taking clozapine, sedation; if you dose off during the day you wake up and your clothing is soaked in saliva and particularly at night you're still salivating and when you wake up in the morning the pillow is soaking in saliva and sometimes you're stuck to the pillow. You're having to dispose of bed clothes at a regular basis; it's a terrible, embarrassing, debilitating side effect.

It's so bad that patients will consider stopping clozapine because they don't want to hyper salivate. If they stop taking clozapine then that's an absolute disaster because the relapse rates, the cost of treating the relapse cases is incredibly high.

So once someone starts on clozapine it's very, very important that they stay on it. One of the reasons that they might consider stopping clozapine is hyper salivation; hyper salivation is a very important problem that we need to try and solve.

The standard treatment for hyper salivation induced by clozapine is something called hyoscine hydrobromide. It's just the go to drug that clinicians prescribe. However, there is very little evidence that hyoscine actually works. There has never been any clinical trials of hyoscine in treating hyper salivation and anecdotal evidence from the patients that we have at Ashworth tells us that actually it's not particularly effective; they are still drooling even if they're taking hyoscine.

So we looked round and tried to find on the basis of the feedback that we had from patients at Ashworth, we looked round to try and find some other possible drug which might treat the hyper salivation problem and we found glycopyrrolate which is something which is used in standard care in the US for young children with neuro degenative disorders like cerebral palsy who also hyper salivate and it seemed quite effective in that population so we thought we'll try and do it in Mental Health patients who are adults.

So that's the idea; so we are going to run a feasibility study to see if we can recruit people or a feasibility study to see if people will stay on the trial once they're in it.

The project team; so Inti Qurashi is the CI; he is Consultant Forensic Psychiatrist at Ashworth Hospital and when we had the idea early 2013 we decided to look round and try and recruit a team which might lend us the expertise that we needed in order to get the trial going and get it funded and help us develop the ideas into a viable project.

So Imram Chaudhry is a Consultant Psychiatrist in Lancashire Care.

Fiona Jones is a Service User Researcher at the University of Central Lancashire who is helping us with the Service User and PPI side of it.

Richard Drake, Nusrat Husain and Bill Deakin are well established Academic Psychiatrists at the University of Manchester and lent us their clinical trial expertise and general subject expertise in building a project like this.

We submitted for competition 24 of the RfPB in May 2014 and got funded in December, seven months later and we've just started this year and we'll finish 20 months later in September next year.

Now how did that actually work; it took us 17 months from start to finish with having the idea to actually submitting the proposal 17 months later. So we had the idea when I first started at Ashworth in January 2013 and the following year summer we submitted it.

It took that long because I think it just takes that long to put together a proposal like that; it just takes a lot of time. During that time we re-wrote the proposal several times; we changed the ideas several times; the outcome measures and the design how we're going to do it, all went through an enormous development period whereby we're consulting with other people and getting their opinions about the best way of doing this was.

Up until February of the year we submitted it was going to be an ethicacy study and then from feedback from other people we decided actually the idea isn't strong enough if you have to go for a full ethicacy study we should try a feasibility trial first.

So all the way through this period we're developing the idea; changing ideas; trying to strengthen the arguments behind why it should be funded because we really thought that quite passionately that this was a strong idea that needed to be solved, a problem that needed to be solved, an idea that needed to be funded and we're trying to find the best way of selling the argument and strengthening the argument and this was an important project the needed that funding.

That took a lot of time to come up with those arguments; it just takes that much time particularly when you're working with a project team who are very, very busy and its quite difficult often to get people in a room to have a meeting about these kind of things and so it just takes a lot of time to get things done.

While we're doing that we are also trying to find ways of strengthening the proposal in terms of strengthening the arguments and strengthening the rationale for doing the project in the first place. So we thought if the idea is that hyper salivation is a very unpopular side effect that might contribute to people not taking clozapine and if the current treatment as usual hyoscine is not a particular effective way of treating hyper salivation then it would be better if we had evidence that this is true.

In the literature at the moment there wasn't a lot of evidence so we thought it would be better if we could support those arguments by getting evidence that these things are actually true, that these arguments that we were making were actually happening in real life and so we did a couple of surveys in the hospital to try and strengthen the proposal.

In the Spring of 2013 we ran a little survey amongst Ashworth patients to try and find out what they thought about taking clozapine and what they thought about the side effects, which were the most unpopular side effects and it came out that hyper salivation was the most unpopular side effect of taking clozapine.

We published that in Summer of 2014; we also got some data from patients about how effective they thought hyoscine was as a medication for clozapine and we found that they thought hyoscine might not be a particularly effective medication, which again supports our argument to get try and get this trial funded.

So while we are trying to re-write and strengthen the ideas behind the proposal we are also trying to support those ideas with data that we can get just from patients that we had access to. Both of these things I think really supported and strengthened the quality of the proposal that we ultimately submitted.

We also got a lot of help during this process principally from the Research Design Service who are incredibly helpful throughout the whole process. One of the main things that helped us a lot is going to the RfPB Proposal Workshops that were run by the RDS in April and January 2014 where you may already know about these things but the RDS runs Proposal Workshops whereby if you pick a competition deadline like you're going to try and hit, running up to that deadline there are a series of workshops which help you with costings; will help you with study design; which helps you and gives you feedback, specific feedback on a draft proposal that you write.

We went to those workshops and the feedback that we got from those workshops were incredibly helpful in helping us to shape the proposal and the design and the way we wrote the thing because as I go on to say later on, it always helps to get as much help as you can that's available. If there's help available why not take it and the help we got really helped us to strengthen the arguments that we were making and strengthen the proposal that we ultimately submitted.

Outside of the Proposal Workshops we also had a lot of contact with the RDS advisers who frequently read stuff and gave us advice on stuff on things like design, statistics and costings.

Outside of the RDS everybody else we knew who was even remotely interested in this kind of thing looked at what we did. Colleagues at CTU that we got involved; we got involved with patients and asked them of their opinions about what we were planning to do.

We solicited as much advice as we could get from everyone we could think of because when you're writing a proposal its very, very easy to get bogged down in a kind of silo mentality when you are kind of pursuing one idea pretty doggedly and if you don't get as many broad opinions as you can, then you might miss things which are quite obvious to someone else who is looking at it slightly more objectively. So by getting as much advice from as many different sources as we could we tried to cover as many of the bases that we thought might come to other people.

What I think helped; principal amongst the things that I think that helped up get funded is having a very useful idea embedded in a very good story. I think the most important thing is to have a very good idea in the first place.

As strong as your PPI is, as strong as your team is if you don't have a very good idea then it's not going to get funded probably because at the very heart of it the RfPB are funding an idea which they want to see come to fruition.

So we thought we had a very good idea; the problem is I don't think at the start we were selling it particularly well because it's a very technical idea; it's a very technical problem that's embedded in a very specialist population. So in order to try and sell it; in order to try and emphasise the importance of this problem we have to try and get creative in terms of what stories we could tell around selling the idea.

So a lot of the development time in terms of the 17 months from start to finish was involved in trying to come up with a way of making it sound like a very important problem and making it sound more attractive to RfPB and emphasising the fact that it's about patient benefit.

So talking about the costs of doing nothing; talking about what the benefits would be if this idea changed and just telling the idea as convincingly as possible. So having the idea isn't enough but selling the idea as well as you can is probably better.

We were able to draw on a very strong project team; so we were able to recruit a good team of clinicians with clinical and research experience; so the Manchester Academics were very good at helping us broadening out the project team and lending us their expertise in both project design and clinical experience.

Having that good track record of working in Mental Health; having a good track record of delivery trials was very important because both Inti and I have never held a major grant before and so we are fairly new investigators in the Mental Health field having a strong team behind us and giving us support really reassured RfPB that this project, if it was funded, would actually come and deliver.

Without that strong team behind us I don't think we would have got funding because I don't think we had the experience of a team to do it ourselves. So having a good project team really strengthens the panels view I think that if the project does get funded it will actually deliver at the end.

All the way through we had strong PPI involvement; so all the way through from the start the idea came from the patients; we consulted with our patients all the way through to ask them what they thought about the design that we had. What they thought about the different drugs that we're trying to test and what they thought about the project in general and their feedback always informed our thinking about how the next draft of the proposal should go.

We also recruited our Service User researcher who is our named applicant on the project and so we tried to make it very clear that PPI wasn't just a token exercise on the project; it was actually a very strong involvement of PPI from start to finish in terms of design and execution and we got lots of our advice. We just asked everybody we could think of who was involved to ask them what they thought our stuff; from RDS advisers to CTUs to colleagues to patients and critical friends, everyone who we thought would give us a useful opinion. We got as much advice as we could.

Two main things; takes longer than you think. So when we had the idea January 2013 we literally thought it will take 4 or 5 months to put together and we were literally aiming

for the May 2013 competition - didn't happen. We then aimed for the September 2013 competition – didn't happen. We then aimed for the January 2014 competition – that didn't happen either.

Now some point during this year we could have gone for it; we could have submitted in January 2014 and if we had really pushed we could have done that but it wouldn't have been as strong an application because there are still some things we were twiddling around with; there were still some things we were debating about and we could have submitted in January but we didn't because we knew that once we submit that's kind of it. You can't go back and change it afterwards and so whatever we did we wanted it to be the strongest application we could possibly put together and didn't want to go at it kind of half cocked.

Even though we could have gone for it in January we held back and tried to refine it some more and actually I'm quite glad we did because we did make some quite important changes in between January and May.

But my advice would be don't rush it because it always takes longer than you think and also it you do try and submit something make sure that when you do it is the best possible version of the proposal that you can possibly put together because otherwise if you don't get funding you're going to be thinking, well if I had made those changes would it have been better. It's better to make sure that whenever you submit it's the best one you could possibly put in.

The second thing is advice; ask for advice and whenever someone provides criticism listen to the criticism.

I have been an academic for a long, long time and the thing about being an academic is that you sometimes have very strong ideas about how things should go and then when someone criticises and gives you advice you think, well, that's what you think but I think something different and I'm not going to listen to what you said because actually I think better.

What I have learnt through this process is that whatever you do ask for criticism and ask for advice and someone tells you something which you kind of disagree with its best to listen to it because you've asked someone's opinion for a reason because you value their opinion and if they then come back and tell you something, which you might not really

want to hear, then that's a good thing because its making you think about something which you haven't thought of before. It's never a bad idea to think about something that you haven't thought of before so whenever someone does give you criticism listen to them; you don't necessarily have to act on it but at least consider it and think about how this might influence what you're doing because otherwise you're working in silos without really having to ask anybody else criticism or ask anybody else's advice and that's always a bad thing. I think that's all I have to say thank you.