**Minutes for Meeting with Client, UCB**

**Date:**

Friday 13th January

**Time:**

10:00 – 11:00

**Participants:**

Michael Sokolovs

Emily Lane

Methelan Jeyaukmar

Walter Gutierrez

Tommy Cheng

Sarah Whitmee

Fiona Grimson

Rachel Tham

**Purpose**

A meeting set up with the client as an opportunity to ask questions, find out more information and clarify any uncertainties prior to commencing work on the research questions.

**Agenda**

**Question 1:**

1. **Why are you carrying out this research?**
2. **What is the purpose of the study?**

**Fiona**:

* Epilepsy is one of the therapy areas that UCB interested in, they have a long history of working in epilepsy and its one of our main focus areas as a company
* Learning more about it and possible ways that the company can improve care is of interest

**Rachel**:

* It’s a broad field, there is some interest to understand if it is changing over time with new drugs and how that landscape has shifted etc.
* Interesting to see what has happened in the past and how things are changing and growing and adapting to new therapies

**Summary**:

* UCB have a history of working with epilepsy, interested to find out more about it.

**Question 2:**

**Who are the end users of the report? i.e., mangers, statisticians, or is it general purpose.**

**Fiona**

* Medical affairs or market access colleagues, so not necessarily statisticians, they won’t necessarily have background in maths or statistics
* Some colleagues might work in health policy or health economics, they are interested in learning about ins and outs about how epilepsy is treated because they have the ultimate goal of bringing UCB products to patients through negotiation with MHRA and NHS etc.
* Medical affairs colleagues also interested in bringing therapies in patients who need it but their perspective in more in the medical community so understanding doctors, how doctors are treating epilepsy, what challenges they have.
* All these colleagues interested in learning about how epilepsy is treated

**Rachel**

* Medical affairs team usually very medically trained so they have deep knowledge of different therapy areas and the drugs and new lines of therapy. They have an interest in positioning the UCB drug and navigate how that changes the environment, whether that be possibly for women of childbearing age or a different purpose of showing UCB drug still holding up to their true standard
* The market access typically works with payers to help subsidize or pay for the drugs, so here it would be NICE which helps NHS reimburse for drugs

**Fiona**

* Expect that they will be quite familiar with epilepsy terms like names of drugs and things like that
* Probably less so with statistical details and specific models that we may use, so would need guidance in those sections

**Summary:**

* A mix of different colleagues but generally they will have knowledge of technical terms related to epilepsy but not have much of a background in mathematics or statistics

**Question 3:**

1. **Main research question has three subcomponents, can you prioritise based on your preferences if we are not able to carry out all three within timeframe.**

**Rachel**:

* Second point (other characteristics of prescribing patterns) – interesting

*Are there any other characteristics of each general practice’s population that are associated with prescribing patterns?*

* Third point (pandemic NICE guidelines) – quite current, interesting

*Have patterns in prescribing changed after: (1) the start of the COVID-19 pandemic, or (2) the NICE 2022 guideline for epilepsy?*

1. **Third question: NICE published in April 2022 so there’s a chance we may not have enough data. If this is that case, is it okay to truncate to part of COVID pandemic**

**Fiona**:

* Yes, make an assessment and see and if there is not enough data for NICE, make decision based on impact
* If not can use COVID data

**Summary**:

* Prioritise second and third bullet point if there is not enough time to complete all secondary questions

**Question 4:**

**If we have any issues or need clarification on any points, can we contact you?**

**Fiona**:

* Yes, we are here to give you a brief but if it does go into a new direction wouldn’t be too much of an issue but feel free to ask questions:

[Rachel.tham@ucb.com](mailto:Rachel.tham@ucb.com)

**Summary**

* Client happy to be contacted but we may need to run this by Tom for approval

**Question 5:**

**Geographical region - what does this mean in context of this question? How granular would you like to go?**

**Fiona**:

* No fixed opinion, based a little on what data you have, can be flexible
* Previously when working with UK datasets, would expect quite high level, not sure how granular, multiple ways to divide the UK, administrative, county etc
* For England start with largest regions and go more granular if need be

**Summary**:

* High level is fine, flexible from client perspective

**Question 6:**

1. **Are there any specific patient characteristics that you are interested in?**

**Rachel**:

* General characteristics first: age, sex, smoking status, alcohol consumption, pregnancy information, childbearing age, autism, other behavioural comorbidities

1. **Would you be interested in index of multiple depredation – I think data doesn’t go granular level or patient level but If linked to geographical index and look at the proxy of chronic diseases or housing would that interest to you?**

**Fiona**:

* Yes

**Summary**:

* General patient demographics – special interest in woman of childbearing age/pregnancy

**Question 7:**

**Time period - you say since beginning of pandemic, so is this a general timeline, any more specifics on this, what window are you particularly interested in?**

**Rachel**:

* For question on pandemic see patterns prior to pandemic and see how things have changed during the pandemic, particularly with how people were not going out and about, and see if this is reflected in the data or not

**Fiona**:

* I think it changed the way people interacted with doctors and GPs in first lockdown, how people were getting their prescriptions and filling their prescriptions, interesting to see how that change in people’s behaviour is reflected in data

**Summary**

* Interested in seeing the different between before and after pandemic started and before and after first lockdown patterns

**Question 8**:

**In relation to drugs, do you want to explore all of them or just specific ones?**

**Rachel:**

* They are specific categories; some are quite old and have been around for some time
* Ion channel modulators – quite interesting. Few UCB drugs in there so that would be of interest
* Modulator of presynaptic machinery – that would be interesting too
* Might be challenging but GABA, enhancement of the GABAergic transmission
* Some of these might have multiple indications which they are used for, so might be difficult to find out if drug is specifically use for epilepsy or something else, so this one (GABA) might be difficult

**Summary:**

* Some interest of certain drugs mentioned above

**Question 9:**

1. **Do you have a preference for format of deliverables?**

**Fiona**:

* PowerPoint probably best format, easiest to share with colleagues

**Rachel:**

* Agreed, universal and best for less technical people
* Would be useful to see tables and plots etc even if given separately in excel

1. **Would it be helpful to present to UCB team with PowerPoint**

**Fiona:**

* Can be arranged, we have a presentation already in a few weeks
* I am holiday but we can invite some other UCB colleagues on the day

**Summary**:

* PowerPoint

**Question 10:**

**We’ll produce some reproducible code, do you have a preference for the software, i.e., python or r?**

**Fiona**:

* Typically, technical people here use SAS but r would be preference of the two

**Question 11:**

**Do we consider mother child relationship for epilepsy?**

**Fiona**:

* Yes if it’s possible, not sure if data is there to address
* If data is there, Rachel mentioned, one of the patient segments we’re most interested in is women of childbearing age - pregnancy is related to this

**Question 12:**

**Can we draw upon external experts with specialised knowledge in epilepsy and do you have any contacts?**

**Fiona**:

* Yes, can contact them if you need an epilepsy specialist
* Email and we will follow up with specialist at UCB

**Question 13:**

**Should we consider adverse effects i.e., birth defects?**

**Rachel**:

* Could be interesting to see adverse events and if there is an increase in events, adverse event tracking
* If available for pregnancy that would nice, although that can complicate analyse
* If too complicated, the main questions posed can be prioritised

**Question 14:**

1. **Any other specific comments or wishes apart from what we’ve covered that would make this research more useful to yourself?**

**Rachel**:

* Would be interesting to see the drugs that incur higher cost than others

**Fiona**:

* When we talked about how usage of drugs has changed, can think about that not just in terms of prescriptions dispensed but also about cost

1. **Quite a few epi drugs there, would you also be interested in the ones with multiple indicators?**

**Rachel**:

* Do realise the cost and frequency might be influenced by having more than one indication, this could complicate the interpretation of it, but think it would be interesting to see if there are some that have bigger market share or less cost but used with same frequency,
* Any kind of difference and what’s leading to these discrepancies would be of interest

**Summary**:

* Some interest in different drugs and costs and patterns related to them

**Question 15:**

**Wanted to ask about specifics about data visualisation, any specific plots, and diagrams you’d like to see?**

**Fiona:**

* Nothing specific – nice to look at geographical trends so there is an opportunity to use nice maps, people always enjoy those

**Rachel:**

* Like the geographical proposal, always then nice to see heat map, also don’t want to restrict creativity so if it deviates from this then no problem, we welcome it
* Another plot often associated with treatment patterns and different line of therapy - sand key diagrams. Can be interesting if that can be associated with different lines of treatment that NICE recommends

**Summary**:

* Flexible but nice to look at geographical trends (heat maps and sand key diagrams)

**Question 16:**

**Are you aware of any similar studies that have been done before?**

**Fiona:**

* Must be lots but none come to mind, can do a literature search on PubMed can find studies in epilepsy treatment patterns,
* Always of interest from pharma perspective, when companies develope a new drug - in addition to establishing the safety and effectiveness of drug through clinical trials they also do research outside of clinical trials to show what the burden of the disease is, what’s the burden on the patient, what’s the burden on healthcare system, what’s the need for therapy in this area –
* A lot of that research gets published so given how many different epilepsy drugs there are and how many are development, I’m sure there are lots of studies looking at treatment patterns for epilepsy

**Rachel**:

* Been involved in a few that are involved with different lines of therapy, but they haven’t used open prescribing, so this is new dataset for me, don’t know if it was published as it was halted

**Summary**:

* Nothing specific comes to mind but worth looking up – not aware of any that used Open Prescribing

**Question 17:**

**Anything from you Sarah?**

**Sarah**:

* Nope, looks interesting, looking forward to seeing the results

**End**

**Fiona**

* Will try sign in from New Zealand, good luck