

## Interview Topic Guide

# Attitudes towards researchers using social media for detecting and monitoring side effects of treatments

### Introduction

Thank you very much for taking part in this study. My name is Su Golder and I work at the University of York. As you know, we are carrying out some research on how people feel about researchers using social media for detecting and monitoring side effects of treatments. Lots of people use social media (such as Twitter, Facebook and discussion forums) to post information on side effects that they or someone they know have experienced.

Potentially researchers interested in the side effects of a particular drug or treatment can search social media using sophisticated technology to find these posts.

This interview is very informal and completely confidential. Only my colleagues and I will see it and your name will not appear in anything we write.

With your permission I would like to record the interview. This is so that I can concentrate on what you are telling me rather than spending the whole time taking notes. Is that OK? The recordings will be stored securely and destroyed after 3 years after the study is complete.

Before we begin do you have any questions?

## **Main Questions**

### **Background about social media use**

To start off, I would like to find out a little bit about your experiences of social media

So can I start by asking you which social media sites you use? How often do you use social media sites? How often do you post on social media? What do you use social media for?

### **Health information online**

Do you ever look up health information on social media? Why or why not?

Do you ever post or discuss health issues online?

### **Reporting of side effects (side effects are effects that are in addition to the intended effect of a treatment and can be harmful or unpleasant)**

Have you ever posted or mentioned a side effect of a drug or other treatment on social media?

Have you ever told a health professional, such as a doctor or nurse about a side effect of a drug or other treatment?

Have you ever told a regulatory agency (for instance by using the Yellow Card scheme in the UK), or a drug company or manufacturer about a side effect of a drug or other treatment?

Have you ever told anyone else about a side effect of a drug or other treatment?

### **Attitudes towards researchers using social media (Some researchers are using social media to carry out their research for example, looking up opinions or forecasting general elections. This is now becoming increasingly common in healthcare research so researchers can predict disease outbreaks or find out about patterns of drug use)**

How do you feel about researchers using social media posts to look at health information, such as monitoring the spread of an epidemic or illegal drug use?

How do you feel about researchers using social media posts to identify side effects? Is it different to other types of health information?

### **Different types of research or researchers**

Does it make a difference who is doing the monitoring for side effects?

Do you feel differently about say an academic from a university, a charity, the NHS, a private company (such as the pharmaceutical company or its competitors) or government body?

Does it make a difference which social media are used for monitoring side effects?

Do you feel differently about different social media platforms (public vs private, Twitter vs Facebook, Health discussion forums, chatrooms)?

### **Privacy expectations**

Do you know who is able to view or monitor your social media posts?

Some researchers have said that using social media data poses no ethical issues because users understand there is no privacy in social media. How do you feel about that?

Do you expect researchers to ask for your permission to use your posts?

What about if the researcher wants to count the number of posts with a specific side effect? E.g. '58 people posted that they suffered from weight gain after receiving drug A'

Or what about if the researcher wants to quote you describing a side effect? For example, 'I've started taking drug A and it has made me put on loads of weight'.

If permission is required, how do you think the researcher should gain this? Should they try to contact you and ask you for permission? Should individual sites ask if you are happy for your posts to be part of research? Could something be included in the terms of service that you agree to when you use the site?

Should they disclose they are a researcher? For example, in chatrooms or discussion forums.

Do you expect to be made anonymous if your post is used in research? Is it enough for researchers to exclude your name? Or should they remove all identifying clues from any posts quoted in their reports or publications?

If you are quoted do you want to be named and given credit for your post?

### **Research Conduct**

If you agree that social media can be used for identifying and monitoring side effects, how should such data be collected and used? For example, do you think there should be any conditions or terms that need to be followed? Are there any laws or rules you would like to see followed?

### **Anything Else**

Is there anything else you would like to add?

Can I ask which age category you belong to 18-30, 31-45, 46-65, 65+

**Thank you very much for taking part.**

If you would like a summary copy of this research please let me know.

