COVID-19 Community Involvement Zoom Call 16.04.20

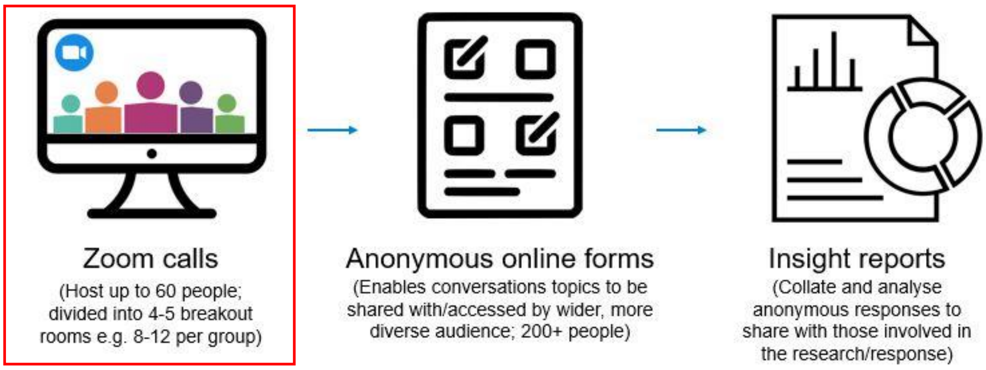
Conversation Insight Report: Digital Contact Tracing

Background

As part of the COVID-19 outbreak response, the Patient Experience Research Centre (PERC) is carrying out a community involvement initiative to rapidly capture the opinions, experiences, preferences and unmet needs of communities in the UK during this outbreak, in an attempt to:

- Guide COVID-19 research at Imperial College London across areas of (1) mathematical modelling, (2) health and biomedical research, (3) engineering and innovation, and (4) socio-behavioural research
- Inform the UK's outbreak response more broadly
- Highlight key unmet needs amongst diverse communities
- Inspire new ways to rapidly engage and involve communities remotely during a public health emergency

Following some early online community involvement at the start of March (see Imperial College London COVID-19 Response Team Report 14), PERC are now looking to optimise and expand the process of community involvement in COVID-19 research and response planning, to ensure the voices, experiences and concerns of those who may be most affected by the outbreak are heard. This includes establishing a regular series of activity that enables rapid input from members of the public into key discussion topics that can be shared in the form of anonymous insight reports.



Call overview and agenda

On Thursday 16th April 2020, we held our first pilot of the community involvement zoom call (4:30–6pm), which was attended by 24 members of the public from across the UK. The majority were relatively experienced with public involvement in research, but some were new to this concept.

The agenda for the call included (1) An introduction to PERC and our work; (2) An overview of COVID-19 research at Imperial College London; (3) Recap of PERC's community involvement initiative; (4) Pre-Discussion Polls; (5) Breakout room discussions (4 rooms; 6-8 people per room) on two discussion topics: (i) Digital Contact Tracing (e.g. via mobile phone apps); and (ii) How the COVID-19 outbreak is being communicated to the public; (6) Next Steps and Questions.

This report summarises the conversations captured around **Contact Tracing Apps** only. A separate report is available for 'How the COVID-19 outbreak is being communicated to the public'.

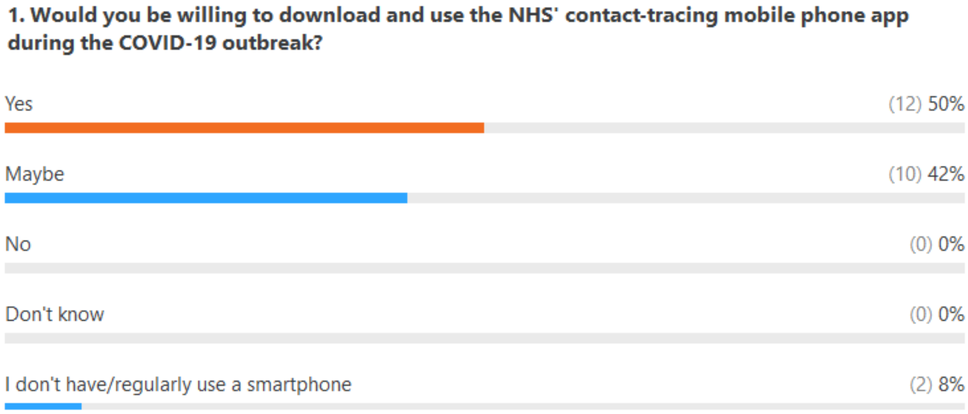
Key Insights Summary

There was overall agreement that a digital contact tracing app was necessary. Those that were considered high-risk individuals felt that without this app, they wouldn't be "released [from isolation] until 2021". However, respondents also felt they would need clear and concise answers to key questions and concerns in order to use and trust a contact tracing app. These fell across a number of key themes that are expanded on in the next section but the key messages that came from through during the conversations are summarised here for ease.

- **Overall support to download/use the app and follow guidance, under the right circumstances**.
    - 50% of attendees said they would download and use the app, 42% might use the app, and 8% did not have or regularly use a smart phone
    - Most reported being either 'likely' or 'very likely' to self-isolate in response to an alert that a recent contact had self-reported symptoms (83%; n=20); or tested positive for COVID-19 (100%; n=24)
    - Notably, respondents showed a drastic increase in being 'very likely' to self-isolate if someone they had been in contact with had tested positive, as opposed to self-reported symptoms (46%; n=11 vs. 83%; n=20)
- **Strong support for users to be able to request follow-up with a healthcare professional (HCP) after receiving an alert from the app.**
    - Many also felt it would be important that those who self-reported symptoms via the app were followed up by an HCP, and ideally tested, so those who received an alert could come out of isolation if the person's test was negative or request their own test if the person tested positive.
- **Need for clarity around practical and privacy questions, including:**
    - How the app works (e.g. What would count as "being in contact" with someone… distance? duration? How will false positives be avoided? Is it safe to keep Bluetooth on all the time? etc);
    - Who was involved in its development and how the data will be used (e.g. How will the data be collected and stored, and for how long? Will it truly be anonymous?
    - What the alerts mean and how they should respond;
    - Why a contact tracing app is needed and how it will be used during the outbreak.
- **Areas flagged for further work included:**
    - How the app will be communicated and launched to the public; and
    - How to support contact tracing among populations who do not have access to data or smart phones.

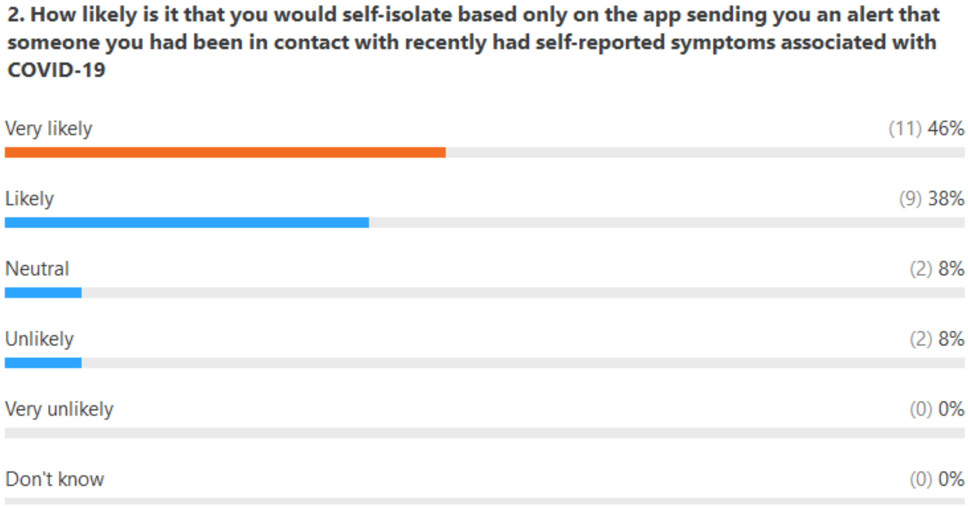
Polls: Use of Contact Tracing Apps

Before the breakout room discussions, attendees were given a brief introduction to contact tracing mobile phone apps, including why they are needed, how they may work and what is required for them to be effective. This was then followed by a series of poll questions that were completed by all attendees (N=24).



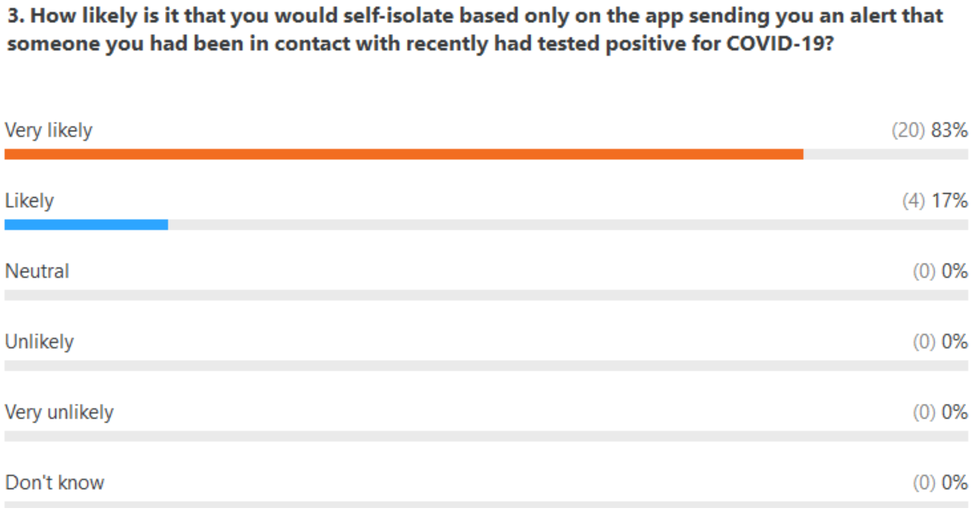
1. Would you be willing to download and use the NHS' contact-tracing mobile phone app during the COVID-19 outbreak?

Yes	(12) 50%
Maybe	(10) 42%
No	(0) 0%
Don't know	(0) 0%
I don't have/regularly use a smartphone	(2) 8%



2. How likely is it that you would self-isolate based only on the app sending you an alert that someone you had been in contact with recently had self-reported symptoms associated with COVID-19

Very likely	(11) 46%
Likely	(9) 38%
Neutral	(2) 8%
Unlikely	(2) 8%
Very unlikely	(0) 0%
Don't know	(0) 0%



3. How likely is it that you would self-isolate based only on the app sending you an alert that someone you had been in contact with recently had tested positive for COVID-19?

Very likely	(20) 83%
Likely	(4) 17%
Neutral	(0) 0%
Unlikely	(0) 0%
Very unlikely	(0) 0%
Don't know	(0) 0%

Breakout Room Discussion Themes

We have performed a very top-line rapid analysis of the key themes that came through during the breakout room discussions and summarised below the main points that were raised. For transparency, we have also included the original discussion notes at the end of this report, see **Appendix 1**. Full discussion notes from small group discussions on contact tracing, which informed the rapid analysis of key themes.

Privacy

Discussions included debates between the need for privacy and anonymity and the desire to support the social good. There were some notable concerns around privacy. While some individuals reported they would want to know who they had been in contact with, or information about known cases' behaviour, most attendees strongly felt that the data should be anonymous. Many respondents were not comfortable with GPS data, as it felt more personal and they didn't like their location being identifiable. However, some respondents also noted that data security advice suggests not using Bluetooth, as it can pick up personal data. While they were less concerned about their contact tracing data, they were concerned about having Bluetooth on for prolonged periods of time as it relates to banking and other personal data that might be linked to mobile phones.

Trust

This primarily related to discussions around how their data would be handled but is highlighted as a separate theme due to how strongly it influenced people's decision. Respondents felt they needed to be able to trust the people behind the app "that what they say is true will be true", but many now felt "the government can't be trusted" due to recent actions. Because of this, there was scepticism that an app in which the government had oversight over would be completely anonymous. There was a sense that there's "a rule for everyone but themselves". Some respondents said they were more likely to trust a solely NHS-led app or one developed in partnership with entrepreneurs (e.g. Bill Gates) than with the government. One also cited Captain Tom as somebody they would trust. Several felt it would be important not only to include the public in the development and communication of the app, but also to mention that members of the public had been involved in the process to help build trust with the rest of the community.

Some individuals noted that current stigmatizing and hateful rhetoric was increasing in their communities (via mediums like neighbourhood discussion forums). For this reason, people felt that how data was handled would be very important to ensure that the app did not inadvertently create social divides or promote stigmatisation both of those contracting COVID-19 and those that chose or were able to engage in the contact tracing exercise or not.

Reliability and follow-up

Concerns were raised by many about the reliability of self-reporting, and what that might mean for repeated exposures and self-isolation. Individuals noted that research shows individuals over and under report symptoms for wide ranging reasons. If the app were only taking self-reported symptoms (even using a model which predicted the likelihood of infection), attendees felt less willing to self-isolate and less confident in the reliability of the data.

Follow-up after symptom reporting was a highly discussed topic. Attendees felt strongly that self-reported symptoms should be followed up in some way, whether by a healthcare professional by phone or chat, or using follow-up questions via the app. Additionally, many also wanted the option to request follow-up guidance from their GP or a healthcare professional after receiving an alert to discuss things such as 1) what the alert means, 2) what action they should take, and 3) how to arrange for a test.

There was also concerns that apps relying on Bluetooth signals “could create a significant number of false positives”. People wanted clarity around how the app’s signals would differentiate between walls, partitions and open space. A specific example given was a passenger upstairs on a bus with a mobile inside a bag on the floor, while a pre-symptomatic passenger infected with COVID-19 sat downstairs with their phone to their ear. Respondents were interested to know if such examples could give rise to a false positive, and if so, how they could be avoided.

People’s likelihood to self-isolate following an alert was linked to their own personal circumstances though. For some, they were more likely to self-isolate in response to being in contact with a known positive case than just self-reported symptoms. While those who were themselves in a high-risk category, or living with somebody in an at-risk group, felt they had no choice but to self-isolate regardless of the scenario because they “can’t afford to take the chance”. Many individuals did say they may self-isolate prior to confirmation but would prefer confirmatory tests with the results shared to reduce the number of days in unneeded isolation. Some also felt it would be important to be able to access a test for themselves. Self-isolating can have a huge impact on some people, particularly if they are a carer for somebody, so they would need instant access to support during this time and wouldn’t want to have to do it multiple times unnecessarily. The overall sense from the discussion was that an alert alone was not enough of a hands-on approach to support individuals.

Logistical concerns

While logistical concerns came up less often a few notable points should be examined further: (1) the impact of using Bluetooth on phone battery life, (2) the impact of using Bluetooth on data consumption, and (3) how to support contact tracing among populations who do not have access to mobile data or smart phones. While estimates do suggest that enough individuals in the UK have access to smart phones, not addressing these, and other issues, may make the contact tracing less effective and leave out vulnerable groups.

Communication and launch

Communication around the app and its launch were a focus of discussions and is relevant to all of the above themes. Communication about how the app would maintain privacy and security was felt to be essential to be able to make an informed decision about downloading and using the app. This was a primary driver for the high rate of “Maybe” responses in the poll. The concerns raised highlight that there is quite a bit of information missing, which attendees felt would be necessary to support personal choice to engage in contact tracing exercises. This included clarity around (1) what would count as “being in contact” with someone (Distance? Duration?); (2) how the app works; (3) what the alerts mean; and (4) why it’s needed.

Next steps and recommendations

Rapid and early engagement with the public is an essential part of outbreak response. The insights shared within this report highlight just some of the concerns and questions the public have around contact tracing apps. Ongoing engagement and involvement with the public is essential to improve the understanding, acceptance, adoption and appropriate use of these apps in the UK once lockdown is lifted.

This pilot call has already provided rich insight into people's current understanding and knowledge around contact tracing apps. It has also highlighted the kind of questions and concerns that would need to be clarified in order to improve acceptance and adoption by the general public. More should now be done to expand the diversity of views that are captured and fed into ongoing work.

PERC would be open to facilitating further sessions like this with the public, alongside key researchers working in this field. These could allow more in-depth conversations around specific aspects, and/or broader input from key groups of interest, such as young people or over 70s. We have also drafted an online form that covers many of the same questions but would enable a wider, more diverse audience to input their perspectives on this topic.

Finally, while we have performed a very rapid thematic analysis of the responses, we highly recommend that you read **Appendix 1** of this document (p6–14) to see the detail of the discussions that were had and gain greater insight into people's specific concerns.

Appendix 1: Full discussion notes on Topic 1 – Contact Tracing Mobile Phone Apps

All staff members that facilitated a breakout room were asked to summarise the key comments, concerns and suggestions that were raised. These are shown below and have not been edited or tidied due to time restraints. These can be used to guide and inform those involved in the development and communication of the contact tracing app, but we ask that they are not edited or used outside of this document. If further or more formal analysis of this session is required, please contact the Patient Experience Research Centre on ppi@imperial.ac.uk.

Breakout room 1

Concerns raised regarding people living in care homes and sheltered housing during general discussions at start of breakout

- Privacy / ethics
    - Concerns this type of surveillance is “like 1984” (Big Brother)
    - Concerns of other potential uses of data and scope of app (or cookies) - who owns the data?
    - Guarantees should be provided in terms of retention, use and secure storage/handling of data – what is the time period?

- Datapoints collected
    - One person thought no personal data should be stored but simply datapoints of person X and Y – where and when they were in contact (not age, gender, etc)

- Logistics and scalability
    - Some felt that if only symptoms were required, you would be “self-imposing” quarantine on someone
    - All agreed with using contact tracing in case of a confirmed case by testing. The app should be used alongside testing
    - Some raised issue that you would need a high uptake in order for it to be an effective measure (one person quoted BBC news of around 80%?)
    - Campaign might help to build momentum (e.g. celebrity endorsement to engage young people)

- Messaging
    - Clear messaging of data collection and retention policies would give confidence in process
    - Clarity would be needed regarding the time point people would need to quarantine/self-report if experiencing symptoms (e.g. as soon as notice cough? Frequency of cough? etc)
    - Clarity on outcomes if people comply and aims of project – what are you trying to achieve? I.e. understand how transmission is happening
    - Clear messaging on the process of using app (e.g. when to/not to)

- Vulnerable / marginalised groups e.g. low income, elderly
    - Concerns raised if cannot access smartphones – what would happen?
    - Suggestion that mobile phone providers provide free data
    - People living on estate /sheltered accommodation may not be able to comply with ‘containment’ as easily as physical building results in contact between individuals

Breakout room 2

- One older gentleman (in his 80s) felt the app was essential because without it, being the age group/risk group he is, he probably wouldn't be released until 2021
- But he said he seldom has his phone on him unless he knows he's going somewhere with wifi
- Some wanted to know what was meant by prolonged contact - perception was that walking past someone would mean contact but Helen said it would need to be prolonged contact e.g. 10/15mins+ (standing in a queue for example) and within a close transmissible distance of someone (i.e. <2 metres)
- Many felt they would want follow-up by a HCP. Concerned about reliance of self-reported symptoms - some people have friends who are hypochondriacs, people with allergies during Spring/Summer etc, or else concerned about malicious use
- Group felt there would need to be really clear instructions on how it works including details above
- Privacy issues raised but felt less of an issue when Helen said that it would be anonymous and using Bluetooth (where phones talk directly to each other) rather than GPS which would pinpoint your location
- Trust was raised as a very very important issue. People would need to trust that what is said to be true will be true.
- Everyone felt strongly that "the government can't be trusted" but they'd be more likely to trust an NHS app OR they would trust Captain Tom ☺ so suggested it was called the Captain Tom app, one also felt Bill Gates and other entrepreneurs were more trustworthy than politicians
- One group member said it would be important to mention that the public were involved in the apps development, but also that the public must be involved in all stages including how it's communicated

Breakout room 3

Fear and stigma

- Note of increased hate messaging on neighbourhood and other forums
- Concern that an app might promote hatred or stigma within communities -even if it is anonymous
- Some new public health interventions have negative implications for using or not using – there were concerns about not using the app potentially having affects down the line (ie health insurance)

Privacy v. social good

- Debate about the line/necessity between the social good and privacy argument
- Privacy concerns:
  - How the data is collected and stored, and for how long – related to the COVID app
  - Data security advice currently suggests not keeping GPS or Bluetooth on all the time because it can lead to compromised data (i.e. bank accounts) – concerns about broader data security by engaging with app
- Social good:
  - Times of crisis call for a loosening of typical views/values
  - The app will protect everyone – including you at a later date so is important

Logistics

- Related to privacy GPS was not wanted as it was seen to be more invasive
- Logistically having Bluetooth on all the time may drain phone's battery – question of what happens if you can only leave this on half the day
- See below launch and symptom tracking point – the app cannot be the only point of contact to ensure people use the app

Symptom tracking and contact tracing follow-up

- Concerns were raised about what symptoms are being tracked/what contact means and how this information is processed
    - Algorithms don't always work, and can be less adaptive to changing dynamics or the realities that COVID symptoms can be more varied
- Group would be less willing to self-isolate for 14 days if no testing was done
    - People may be less willing/able to report correctly – hypochondriacs or misrepresentation of symptoms
    - Does this mean you will be constantly be being told to self-isolate – more information about what the process and implications are would be needed to follow advice
- What happens after symptoms are added – Do you just get a screen that says you likely have COVID? What information do the contacts get?
- Quite a bit of discussion that follow-up is needed to try to case identify and better support contact tracing
- Phone calls -personal contact was the most wanted – using NHS volunteers
- 2nd level triage with an additional set of questions or chat like triage feature were also suggested
- Personal feedback would be nice – including if it is not COVID and brief advice on what to do

App launch

- Launch of the app was seen the most integral part to ensuring individual and societal uptake
- Suggestions for launch included using the COVID daily briefings and including app developers (tech savvy folks) to answer questions
- Texting information rather than emailing was seen as more effective
- Additional support was felt to be needed to make an informed choice about utilizing the app – more information on data and privacy, using the app, amount of data it would use, what happens after you submit symptoms etc – see above follow-up of symptoms
- Many apps floating around – questions about if those apps would keep going or would no longer collect data – Noted needs to be very clear to all what app to use and why

Breakout room 4

- I hope they already know that 60% of population own smart phones otherwise it's a pointless exercise.
- No smart phone because doesn't want one as doesn't want to have emails available all the time but if there was a contract tracing app would persuade her to get a smart phone
- Has smart phone – don't disagree in principle but concerned by organisations like NHSX who are involved in making app, re capacity in data collecting, pinpointing who you are, postcode, phone calls so wouldn't download app because of organisations behind it so don't trust it. How could it be guaranteed that no personal data collected by app (as is apparently

the case)? Previous leakages of data have happened on many occasions so assurance that no personal data collected would not make her change her mind.
- Think NHS already have the kind of data collected by app about us so giving information on mobile won't add to it.
- What were the symptoms, if just a cough wouldn't be enough. If lost sense of smell, cough, headaches might be more convinced. Could have a lot of contact with people with a lot of minor symptoms so could be isolating a lot because of this
- Can't be too careful so would self-isolate if contact had symptoms
- Thought app was to prevent us self-isolating all the time so liberating to have app so could get on with normal life.
- Follow up test a few days later after notification of symptoms would help.
- Thought NHS had capacity to test but they had not had enough referrals yet
- Friends have tendency to hypochondria, so they are feeling quite anxious at the moment and don't want to affected by their hypochondria. Have been good at self-isolating so far but it won't last for 6 months.
- If knew within a few days if someone's symptoms were actually COVID would be easier to self-isolate.

Prompt question: If in vulnerable or extremely vulnerable group would you be happy to use app if restrictions lifted?

- Thought was in vulnerable group because told if invited for flu jab would be getting a letter saying in a vulnerable group. Not had a letter so don't know if vulnerable but is self-isolating. Two friends have had a letter. Lack of competency of the government to tell us whether we are vulnerable or not affects my ability to use this app with any great confidence.
- If people have been self-isolating for 12 weeks, are they going to trust an app to tell them who has it or not?
- App would need to run alongside social distancing as well.
- Using the app is a question of trust and if want to use this technology there needs to explanations and training so people can trust it and can ask questions before using it. It won't stop what we are doing but will make people less anxious to support them through isolation or current measures.
- App is a tool to reassure people as well as improve NHS service. It is not a solution.

Prompt question: What about a personal aspect to the app e.g. healthcare worker contacting after notification by app.

- Would feel more confident that data was being used i.e. helping me control my own safety and others safety and following up the data.
- Would prefer just the app as is less personal as don't want everybody knowing my business so app on own would suit me better
- If I got a follow up call it would give me more confidence that someone was aware of my situation
- If got a follow up call would make me trust the app more
- Would add to knowledge of your illness. App, follow up phone call then follow up call to check how doing. All the information is useful.
- Could opt in or opt out for personal follow up contact.

- Reporting symptoms could be on a scale of how unwell they felt. If someone was a little unwell it wouldn't make her stay in for a week. Needs to take in account the degrees of illness.

Prompt question: Anonymous follow up?

- Wouldn't mind who followed up as long as they had my best interests at heart
- Wouldn't mind Government and GP knowing I had been ill but wouldn't want friends and colleagues to know.
- Not happy about people knowing I had infected them ie. being labelled as a super spreader like guy from Italian skiing holiday
- Would want to know that the person who had infected you was self- isolating instead of infecting more people.