Professor Ben Bridgewater, Health Innovation Manchester – Written evidence (COV0038)

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Technology and global preparedness

The GM experience through COVID-19 has been that the need to respond to the pandemic has created an unprecedented ability to drive forward many of the underlying health and care assets in the city region. This note will focus on the GM Shared Care Record. The COVID-19 crisis has highlighted 2 things:

- That our efforts to bring together complete and comprehensive health and care data prior to the crisis were incomplete, due to the complex legal framework, different perspectives of data controllers within that legal framework, and a lack of prioritisation as a key initiative alongside other activities in the city region.
- Once the crisis became apparent and the NHS Level 4 command and control structure was put in place, we achieved massive acceleration of our existing plans.

Over a 6 week period during the COVID-19 lockdown, we accelerated the number of citizens onto our share care record by 1m (an increase of 30% to get to >99% coverage), systematically enriching the data feeds into the record from acute providers as well as breaking down firewalls within the data, that had previously prevented data sharing across localities in order to comply with the pre-existing data sharing agreements. This now enables sharing of the care record for all citizens for direct care across the city region.

Despite the coverage of the COPI notice, this was very challenging to deliver, requiring extensive work across the multiple GM data controllers and data processors. However, by accelerating the care record we have significantly increased utilisation at the point of direct care which is receiving good feedback from users. This has made a significant contribution to our COVID-19 response.

However, despite the legal requirement to share data for the purposes of the COVID-19 response (which includes research), we have still been unable to secure the necessary permissions from data controllers to conduct research on these data. These challenges have inhibited the GM response to the global understanding of the disease, as well as truncated our ability to identify and enrol patients into COVID-19 clinical trials. It has been our experience that the COPI notice has not given sufficient impetus to enable us to respond optimally to the crisis, from the perspective of sharing data for direct care and secondary use.

Now, as we move through the crisis, we have significant concerns that data controllers will return to the previous situation of limited, locality-based data sharing, which will inhibit the optimal response through this and other crises. We suspect that the attitudes which drive these behaviours in data controllers are complex, ranging from a genuine perspective of patient advocacy, through commercial considerations, to fears about performance monitoring. Consideration of these issues is important for both driving a more effective

response to a pandemic, as well as enhancing routine and emergency direct care and secondary uses for non COVID-19 related health and care.

30 June 2020