BMA response to Public Health England call for evidence:

What is the public health impact of the Memorandum of Understanding on data sharing between NHS Digital, the Home Office, and the Department of Health, particularly on health seeking behaviour and health outcomes of the migrant population?

Our submission is based on responses to a cohort survey of our members who have experience with working with this population group. We received 622 responses to the survey from doctors currently working in England – of which 89 doctors indicated that they had experience of working with this population group.

Of those 89 respondents, in response to the question ‘Do you think there is likely to be a public health impact of the MoU data sharing between NHS Digital, the Home Office and the Department of Health, particularly on health seeking behaviour and health outcomes of the migrant population’ the following results were found.

Yes, a significant impact – 43.7%
Yes, a moderate impact – 19.5%
No impact – 6.9 %
Not sure – 29.9%

The following is a selection of quotes from the respondents when they were asked ‘Do you have any specific examples of when a patient changed their health seeking behaviour due to concerns about confidentiality and data sharing?’

‘Non-treatment of severe and enduring mental illness’.

‘Patients refuse to engage with CAMHS even though children have significant difficulties resulted from trauma’.

‘Patients discouraged from seeking medical help’.

‘Women presenting very late for maternity care. Avoiding the GP as much as possible until very ill. Lack of treatment for infectious diseases. No access to mental health support for often very traumatised people’.

‘I have personally experienced people avoiding seeking help from their GP as a result of this, having an adverse effect on them seeking help. As a doctor volunteering at Grenfell there were individuals who [were] avoiding seeking medical attention as they were scared of the result of giving their details’.

‘Patients not coming forward for care’.

‘Yes. A pregnant woman with HIV infection disengaged with care, and was only re-engaged after a great deal of work’.

‘Patient repeatedly DNA[d]’.
‘Trust was affected [by] by formal registration and fear to be noted by immigration office’.

‘A patient in our SARC who was 5 months pregnant was arrested on the premises when reporting a rape and handed to immigration authorities. I’m sure it changed her health seeking behaviour and not for the better’.

‘Patient not attending hospital appt for serious medical problem’.

‘A patient of mine delayed seeking help about a rare ocular tumour due to concerns about her immigration status. By the time the tumour was diagnosed, it had spread and she died at the age of 44’.

‘Yes, did not come for maternity care until 8 months, then presented in labour. Did not seek postnatal care (was chased up by Doctors of the World who helped her).’

‘Yes. Can think of a case that got quite bad before they presented because of the fear of seeking help early’.

‘Yes. Made up name and DOB, and another whom refused to tell us anything about her[self], admitted repeatedly as an emergency to different hospitals’.

The following quotes reflect BMA members’ views on the potential impact of the MoU.

‘People will seek help later or never’.

‘I think they are less likely to seek help’.

‘The population will not seek healthcare’.

‘This will potentially deter people from seeking care about HIV-related problems and STIs’.

‘They will just stop addressing their health needs’.

‘People with caring responsibilities, parents of children with serious illnesses and child protection problems and those suffering from communicable diseases are less likely to come forwards to receive healthcare which in and of themselves present public health concerns’.

‘They will not come for care, it will undermine community relations, people might attend later this morbidity / mortality and potentially more problems with containing infectious diseases (eg TB / STIs)’.

‘Migrants would not be able to trust doctors. This is a population with higher than average mental and physical health problems’.

‘Will deter them for seeking healthcare, causing them to present in a crisis’.
‘If patients believe or perceive their details will be available to the ‘authorities’, this will affect the doctor / patient relationship. Moreover it may deter patients seeking treatment. This would not be good for their health if they had an infectious illness, it may adversely affect others’.

‘Going underground, not seeking help for mental health issues, not seeking help with domestic abuse, authoritarian communities may have greater control over the most vulnerable members…’

‘As a consultant in communicable disease control I am particularly concerned about patients with conditions like TB, which are treated free for everybody. The MoU, however, makes some people less likely to come forward, increasing the risk to others.’

Separate to our cohort survey we were independently contacted by a member voicing concerns about the MoU:

‘I used to coordinate the Immunisation programme across Yorkshire and we had real difficulties in Bradford purely because the Pakistani community merely suspected that their data might be misused in this way, even though we strenuously denied this. There were also problems with getting recent immigrants with bad coughs who may have TB to go and see GPs’.