

**FAO:**

The Rt Hon Matt Hancock MP, Secretary of State for Health and Social Care;  
Elizabeth Denham, Information Commissioner

**CC:**

Justin Tomlinson MP, Minister for Disabled People, Health and Work;  
Helen Whatley MP, Minister of State (Minister for Care);

27<sup>th</sup> March 2020

Dear Sir/Madam,

**Re: Register of Vulnerable People**

We write on behalf of the disabled people we represent regarding a matter of grave concern to us and one which affects all our members. We are asking you to reconsider current strategies regarding the delivery of essential groceries and supplies to disabled and vulnerable people.

**The Issues**

We know that you will be aware that many disabled and vulnerable people are following Government advice to stay at home for at least 12 weeks. Many are concerned that they will lose elements of their care needs and personal support packages as a consequence of The Coronavirus Bill.

We have been contacted by many disabled people expressing anxiety about their ability to obtain food and essential supplies from supermarkets. There is no option for them to attend supermarkets in person, even in line with social distancing obligations, requiring alternative means of arranging delivery of supplies.

Unfortunately, and in breach of their obligations under the Equality Act 2010, supermarkets are failing to anticipate the need to make reasonable adjustments for their disabled customers. Their websites are inaccessible to most blind people who rely upon screen readers. Telephone booking lines, even where supposedly dedicated to disabled people, are inaccessible to deaf people, and those with speech impediments and anxiety. We have received numerous reports of those lines being busy for hours on end, and only to find recorded messages to refer customers to the Government's list of vulnerable people.

We have learned today in a communication sent to customers of Sainsburys that,

"We will receive the government database this week which tells us which people in England the government considers to be most vulnerable. Where these people are already registered with us, we will start to write to them next week to offer them a delivery slot."

Our understanding is that you are restricting qualification as to who should benefit from priority access to services, to the following medical conditions:

- 1) Solid organ transplant recipients.
- 2) People with specific cancers:
  - people with cancer who are undergoing active chemotherapy or radical radiotherapy for lung cancer
  - people with cancers of the blood or bone marrow such as leukaemia, lymphoma or myeloma who are at any stage of treatment
  - people having immunotherapy or other continuing antibody treatments for cancer

- people having other targeted cancer treatments which can affect the immune system, such as protein kinase inhibitors or PARP inhibitors
  - people who have had bone marrow or stem cell transplants in the last 6 months, or who are still taking immunosuppression drugs
- 3) People with severe respiratory conditions including all cystic fibrosis, severe asthma and severe COPD.
  - 4) People with rare diseases and inborn errors of metabolism that significantly increase the risk of infections (such as SCID, homozygous sickle cell).
  - 5) People on immunosuppression therapies sufficient to significantly increase risk of infection.
  - 6) Women who are pregnant with significant heart disease, congenital or acquired.

We are extremely concerned at the implications of both the communication of the register, in respect of the information on it, and the composition of the register itself. Whilst we recognise that the Government proposes to take this action with the best of intentions and to assist tackling the problem we have raised, there are clearly both legal and ethical issues regarding the disclosure of data and the compilation of a state-owned register of people with disabilities.

Firstly, with regard to the disclosure of data, you are proposing to disclose what is presumably confidential data without the subjects' consent in what would appear to be a breach of the Data Protection Act 2018 and GDPR; the data protection principles and in circumstances where the data concerned is sensitive personal data. There is no indication as to how this data will be safeguarded and into whose hands it will fall.

Secondly, and with regard to the register itself, we are concerned that it is built on the medical model of disability by requiring as we understand it an NHS

Number. As long ago as 2015 the Government Equalities Office recognised the Social Model of disability and recommended the model for use by all government departments in the way they interact with disabled people. The outdated medical model recognises people as disabled by their own impairments or medical conditions rather than being disabled by factors external to those conditions.

According to section 6 of the Equality Act, disability is defined as a physical or a mental condition which has a substantial and long-term impact on a person's ability to undertake normal day to day activities. Whilst we are not suggesting that everyone covered by this definition falls into the category of those who require assistance with shopping, it certainly goes beyond the list that you have set out. There are 14 million people with disabilities in the UK. It is estimated that only 1.5 Million people may qualify under the 'Register' above.

We are also concerned that by putting such a narrow interpretation on disability in the context of supermarkets, it will be adopted by service providers generally in the current situation, which would be corrosive to the socially important principles behind the equality legislation. It is our view that in providing such a list to supermarkets you are in effect assisting them in evading their responsibilities under the Equality Act to make reasonable adjustments by for example providing them with assistance to shop.

As an aside, we have grave concerns as to who will be tasked with delivering supplies in respect of the Government's proposed scheme for vulnerable people. Many disabled people will be unable to accept deliveries without assistance, some will have communication difficulties. There is currently no confirmation that the individual making deliveries will be DBS checked, and as to the integrity of the personal information in respect of that vulnerable disabled person. Regardless of the ethical and practical difficulties as highlighted above, disabled and vulnerable people have not opted into your register for

you to pass their personal and sensitive data to commercial organisations or indeed anyone at all.

**What we would like you to do**

We would like you to agree that you will not share information relating to disabled people with any non-state organisation without the express and informed consent of people who have joined that register.

We have taken legal advice from Fry Law and we are ready if necessary, to apply to the Courts to prevent you from proceeding down this route. We sincerely hope this will not be necessary.

We should also add that we are all extremely surprised that the Government is taking such initiatives, however well meaning, without consultation with disabled people and their representative organisations. We will be happy, at very short notice to assist including by meeting with the Government to find an improved solution.

Yours sincerely,

**Personal Data**

Kamran Mallick, CEO Disability Rights UK