

Asthma UK is dedicated to improving the health and well-being of the 5.4 million people with asthma in the UK

Asthma UK Helpline
Ask an asthma nurse specialist
0300 222 5800
asthma.org.uk/helpline

Asthma UK
18 Mansell Street
London E1 8AA
T 020 7786 4900
F 020 7488 0882
asthma.org.uk



National Data Guardian for Health and Care's Review of Data Security, Consent and Opt-Outs

Response on behalf of Asthma UK

Asthma UK welcomes the chance to contribute to the future of health data sharing in England. This issue and the work of the National Data Guardian (NDG) is of great importance to Asthma UK. As a member of both the Richmond Group and the Association of Medical Research Charities (AMRC), we have contributed to their responses to this consultation and fully endorse their submissions.

Single opt-out model

The majority of asthma care takes place in primary care, but there have been tragic consequences where data hasn't been shared appropriately between primary and secondary care. Sadly, there have been several cases of asthma deaths¹ that could have been avoided through the flow of data across sectors of the health care system. We are glad the NDG recognises how important data is to the quality of care. We want people with asthma to feel confident about allowing their data being used both for their care and research. This will require an honest dialogue between patients and the National Data Guardian to challenge assumptions regarding the current system.

Asthma UK welcomes the proposed opt-out format for data sharing. A new arrangement for the use and sharing of personal data needs to be as straightforward as possible to ensure public understanding and buy-in. Therefore, a single opt-out question is preferred. While agreeing with the basic framework proposed, there is a lack of detail in the communication and implementation of this work. This is the main barrier to the successful implementation of the new opt-out arrangement. This work presents a considerable challenge to the NDG. Whilst we recognise that this is a separate project to care.data, without clear messaging the public may not make this distinction and the success of this work may be compromised. A straightforward, positive case on how sharing data saves lives needs to be developed and outlined, and we are happy in principle to help communicate this to our supporters, if the appropriate safeguards on the use of personal data are outlined. The safeguards proposed need to be emphasised in order to build public trust in the proposals. Communication to the public on the scope of the NDG's remit, the levels of potential sanctions and the examples of safe data sharing will contribute to the potential success of data sharing. We believe the third sector has a potential role in this communication of the proposed framework but confidence in the system and comprehensive communication plans are a prerequisite. We look forward to hearing more

¹ A recent example of this is the death of Tamara Mills. <https://www.judiciary.gov.uk/wp-content/uploads/2016/01/Mills-2015-0416.pdf>

Asthma UK is dedicated to improving the health and well-being of the 5.4 million people with asthma in the UK

Asthma UK Helpline
Ask an asthma nurse specialist
0300 222 5800
asthma.org.uk/helpline

Asthma UK
18 Mansell Street
London E1 8AA
T 020 7786 4900
F 020 7488 0882
asthma.org.uk



about the communication and implementation plans. We would welcome the chance to contribute at a future stage.

The role of data in research

The role of health data in research needs to be promoted by the NDG. We know that research saves lives, and the use of health data enables this to take place. Although the proposed consent model mentions the role of health data in research, this needs to be communicated to the public to gain their consent for the use of their health data. Asthma is just one disease that requires significant further research in order to understand the causes and triggers of it, and to eventually cure it. The use of health data is invaluable to this work, but this needs to be explained to the public. Therefore, the NDG needs to take a prominent leadership role in the relationship between patients and their health data. We are pleased that anonymised data in research will not be subject to opt-outs.

Data security statements

The statements on data security are sensible and are welcomed. However, there are certain passages of the consultation document where the language really needs to be precise, to ensure clarity and public trust. Perception of loopholes will cause concern and the public may understandably opt out. Communication of the more complicated elements of the model needs to be as clear as possible to avoid any confusion or misrepresentation. For instance, on page 13 (element 8 of the proposed model), it is stated that the opt-out will not apply 'where there is an overriding public interest' and for the 'monitoring and control of important diseases'. Explicit examples of such scenarios need to be articulated to reassure the patients who choose to opt-out that their wishes are to be respected. We would also welcome more clarity on the training aspect for staff handling confidential data. This exercise needs to be more than a mandatory test, but part of a learning culture in which the NDG is prominent and offering leadership.

Planning and public engagement

The report and consultation document do not contain details of the schedule for implementation. This is a very ambitious but essential project and we hope that sufficient time has been planned to explain and communicate with healthcare professionals and the public, learning from previous experiences. We would welcome the publication of a schedule to develop the necessary internal NHS and primary care and external communications programme required to ensure buy-in and success. Healthcare professionals will play a significant role in ensuring the success of this programme and their support and ability to answer patient's questions accurately will be important.

Asthma UK is dedicated to improving the health and well-being of the 5.4 million people with asthma in the UK

Asthma UK Helpline
Ask an asthma nurse specialist
0300 222 5800
asthma.org.uk/helpline

Asthma UK
18 Mansell Street
London E1 8AA
T 020 7786 4900
F 020 7488 0882
asthma.org.uk



The new arrangement would also have the best chance of success with full testing, and it is unlikely that this could be rolled out with a full evaluation in that timeframe. Once again, we would be very interested to hear about plans for the implementation and engagement plan.

The framework proposed for the opt-out question for the use of personal health data is eminently sensible, but Asthma UK is concerned about the lack of detail in the future planning of the work. Without sufficient communication and engagement with patients, it will be rather difficult for the policy to succeed, and for patient data to flow and save lives. Asthma UK will monitor the development of this work with interest and will continue to take the opportunity to contribute.

Contact details

Andrew Cumella

Policy Analyst, Asthma UK

andrewc@asthma.org.uk

02077864907