Written Evidence Submitted by The Open Data Institute (ODI)
(DDA0068)

Introduction

- In January 2022 the Open Data Institute (ODI) made an evidence submission to this inquiry.[1]
- We've since observed that the Committee has taken evidence on the importance of public trust and engagement activities in the sharing of health data.
- For this reason, we'd like to make a supplementary evidence submission covering new material that was not available in January 2022.

Data literacy for trusted and trustworthy Government data practices

- **Government's pandemic response brought data into the heart of government decisions like never before,** with one Minister describing it as a 'high watermark of data use[2]'. Government use of data is set to become even more fundamental, with the forthcoming Integrated Data Service[3] and government's recent proposals for data protection reform[4] demonstrating a commitment to greater sharing of data between public sector organisations and between the public and other sectors.

- **As the Government does more with data, it is vital that both the public sector workforce and the general public have confidence in understanding what Government is doing with data.** The Government recognises the importance of data skills – 'for a data-driven economy and data-rich lives' – by making it one of the four pillars of the National Data Strategy[5]. Within this, it says that 'foundational data literacy will be required by all'. Data literacy initiatives are vital in Government's attempts to build trust as it embarks on more advanced projects involving data and technologies and techniques, like artificial intelligence (AI), as the public will need some understanding of its plans and products.

- **In April 2022 the ODI published a new report: "Data Literacy and the UK Government"[6].** Our research finds that the UK government:

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[1] See: https://committees.parliament.uk/writtenevidence/43473/html/

[2] National Data Strategy (DCMS, 2020) https://www.gov.uk/government/publications/uk-national-data-strategy/national-data-strategy#ministerial-foreword

[3] ONS launches Integrated Data Service to boost government collaboration on data sharing (ONS, 2021) https://www.ons.gov.uk/news/news/onslaunchesintegrateddataservicetoboostgovernmentcollaborationondatasharing

[4] Data: a new direction (DCMS, 2021) https://www.gov.uk/government/consultations/data-a-new-direction

[5] National Data Strategy (DCMS, 2020) https://www.gov.uk/government/publications/uk-national-data-strategy/national-data-strategy#data-1-2

[6] "Data Literacy and the UK Government" (The ODI, 2022) https://theodi.org/article/data-literacy-and-the-uk-government-report/

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    - **has no consistent definition for data literacy in its workforce or in the wider population,** and therefore no way of measuring it.
    - is at risk of **duplicating its work around data literacy:** several different public sector teams are responsible for 'data literacy' in government, **risking fragmentation, and contradiction**;
    - is **providing insufficient support for data literacy to public sector workers** outside of data-oriented professions and functions;
    - is doing **too little to support data literacy in the wider population**.

- Our report draws on desk research and stakeholder interviews, and **focuses on the 'supply side' – what the government is doing to get the right structures and support in place** – rather than the 'demand side' – such as the public expecting a more data literate government.

- One stakeholder we interviewed used the **Covid-19 pandemic as an example of where the public had driven improvements in government – a desire for more and better data and better presentation at Downing Street press conferences forced government to publish better data and present it more clearly.** They wondered whether similar public demands in the future could help encourage data literacy in government and in the wider population.

- We hope this research complements the work currently underway by others, including the Centre for Data Ethics and Innovation (CDEI)[7] and civil society organisations such as the Ada Lovelace Institute, on the **importance of public understanding, trust and engagement around data and digital technologies.**

Public engagement and public dialogue for trusted and trustworthy Government data practices

In March 2021 our Head of Public Policy, Dr Mahlet Zimeta, was invited to serve on the Independent Advisory Group (IAG) of a public dialogue initiative run by then-NHS Test & Trace (now UK Health Security Agency (UKHSA)) around use of data in pandemic response. This public dialogue initiative brought together a diverse cross-section of society who formed a "Public Advisory Group" (PAG); the structure and timeline of the activity was as follows:

- The IAG met regularly from 31st March 2021 until 7th July 2021. The Terms of Reference for the IAG described the PAG as "engaged to inform current and future decision making, through a deliberative dialogue process. Key to this process is the establishment of an Independent Advisory Group (IAG) to advise the design and delivery of the PAG; supporting it to provide an authentic and meaningful opportunity for the public to deliberate key policy dilemmas and genuinely influence decision making."[8]

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[7] "Public attitudes to data and AI: Tracker survey" (CDEI, 2022)
https://www.gov.uk/government/publications/public-attitudes-to-data-and-ai-tracker-survey

[8] Independent Advisory Group for England's COVID-19 Public Advisory Group: Terms of Reference (DHSC, 2021)
https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/987

- The PAG ran from 10th-24th June 2021. The published purpose of the PAG was to ensure that members of the public, especially those most at risk from the virus, had the chance to feed into the Government's ongoing work to respond to the COVID-19 pandemic. One of the two main focus areas for the PAG set by NHS Test & Trace was "how the government might use data to reduce public health risks and what this means for individual privacy."[9]

- The PAG was designed and delivered as a series of workshops with distinct discussion topics, and a parallel workstream focussing on engagement of marginalised communities. Throughout the process, vulnerable communities were over-represented in the PAG to counter-balance the disproportionate negative impacts on them of the pandemic, and to support more equitable outcomes from the PAG process as a whole.

- The data-related discussion areas at PAG included: data privacy and security around covid test results; data accuracy and anonymity around contact tracing; data about personal circumstances that might be relevant to eligibility for Government support for self-isolating; and data from community wastewater testing as an alternative to individual testing.

- In summer 2021 the published Outcome statement for the PAG was:
    - "At the end of the series of workshops, the organisers will produce a report that presents the views and recommendations of the Public Advisory Group to DHSC and NHS Test and Trace.
    - The group's recommendations will inform critical future policy decisions. This report will be published on GOV.UK"[10].

- However, the report of the PAG findings and recommendations was published on 6th May 2022, over 9 months later than expected. This delay was regularly challenged by the IAG; and by the time the report was published, the statement of commitment to informing Government policy had been removed from the PAG project website on GOV.UK[11].

- In the period between the end of the PAG feedback workshops in June 2021 and the publication of the report in May 2022, the Government announced three major policy decisions around pandemic response:
    - on 8th December 2021 emergency covid restrictions were introduced in response to the new omicron variant[12];
    - on 27th January 2022 these emergency restrictions were lifted[13];

631/ukhsa-public-advisory-group-independent-advisory-group-terms-of-reference.pdf
9 NHS Test and Trace Public Advisory Group (DHSC, 2022)
https://www.gov.uk/government/groups/nhs-test-and-trace-public-advisory-group
10 NHS Test and Trace Public Advisory Group (DHSC, 2021): accessed via The Internet Archive / Wayback Machine
https://web.archive.org/web/20210514090715/https://www.gov.uk/government/groups/nhs-test-and-trace-public-advisory-group
11 NHS Test and Trace Public Advisory Group (DHSC, 2022)
https://www.gov.uk/government/groups/nhs-test-and-trace-public-advisory-group#outcome
12 Prime Minister confirms move to Plan B in England (10 Downing Street, 2021)
https://www.gov.uk/government/news/prime-minister-confirms-move-to-plan-b-in-england
13 England returns to Plan A as regulations on face coverings and COVID Passes change today
 (DHSC, 2022) https://www.gov.uk/government/news/england-returns-to-plan-a-as-regulations-on-face-coverings-and-covid-passes-change-today

- ○ on 21st February 2022 all covid restrictions were lifted[14].

- These developments occurred without the PAG findings being in the public domain, or communicated more widely, for transparency about whether or how Government decision-making had been informed by the PAG results.

Our experience of the delivery of the public dialogue activity was that the delivery team were proactive and responsive to both strengthen the inclusivity of the public dialogue activity, as well as to ensure accuracy of technical content. We also noted processes of transparency and accountability that support public trust and data literacy, such as publishing the meeting minutes of IAG meetings[15] and publishing the PAG workshop materials[16] on the project website on GOV.UK.[17]

However, we would like to bring to the Committee's attention the following areas of concern:

- the **diminished relevance and value of the insights** from the public dialogue activity because of the delay in the publication of the findings, between summer 2021 and May 2022.
- the **dissonance** between the speed at which the exercise was conducted in around 1 month against the delay in the publication of the findings of around 9 months, and how this **might negatively impact participants' perceptions of the trustworthiness of the process and/or of government accountability** for responding to their feedback.
- the **potential negative impact on participants** from the lack of timely follow-through on their contributions - especially since disadvantaged groups who were disproportionately impacted by covid-19 were strategically over-represented in the exercise for more equitable outcomes.
- the **potential negative impact on the credibility of UKHSA**, as a new entity, especially in the shadow of the GPDPR controversy in May/June 2021[18] and other controversies related to the governance of health data.
- the **missed opportunities and missed benefits for wider "lessons learned"** from the management and delivery of the exercise as a whole - both as a template for future public engagement around the use of data, and as an example of UK leadership in an emerging area of international importance.

We believe that addressing these concerns will help the Government to deliver against the mission of the NHS data strategy to "unleash the unlimited potential of data in health and care, while maintaining the highest standards of privacy, ethics, and accountability."[19]

(May 2022)

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[14] Prime Minister sets out plan for living with COVID (10 Downing Street, 2022) https://www.gov.uk/government/news/prime-minister-sets-out-plan-for-living-with-covid

[15] IAG minutes of meetings (DHSC, 2021) https://khub.net/web/phe-national/public-library/-/document_library/v2WsRK3ZlEig/view/548845127

[16] IAG public library (DHSC, 2021) https://khub.net/web/phe-national/public-library/-/document_library/v2WsRK3ZlEig/view/548845070

[17] NHS Test and Trace Public Advisory Group (DHSC, 2021) https://www.gov.uk/government/groups/nhs-test-and-trace-public-advisory-group

[18] Over a million opt out of NHS data-sharing (Computer Weekly, 2021) https://www.computerweekly.com/news/252505760/Over-a-million-opt-out-of-NHS-data-sharing

[19] Data saves lives: reshaping health and social care with data (draft) (DHSC, 2022) https://www.gov.uk/government/publications/data-saves-lives-reshaping-health-and-social-care-with-data-draft/data-saves-lives-reshaping-health-and-social-care-with-data-draft