# MODULE 4

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# CLOSING SUBMISSIONS OF DISABLED PEOPLE'S ORGANISATIONS ('DPO'): DISABILITY RIGHTS UK, DISABILITY ACTION NORTHERN IRELAND, INCLUSION SCOTLAND AND DISABILITY WALES

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## INTRODUCTION

1. OUTLINE: For Disabled people the possibility of successful pharmaceutical release out of the pandemic required them to negotiate an arc of exclusion. There were problems of **Need** (PART I) **Trust** (PART II) and **Access** (PART III) that arose through Disabled people's interaction with the UK's pharmaceutical response to the pandemic, regarding [A] **Development** [B] **Prioritisation** [C] **Delivery** [D] **Alternatives** and [E] **Damage**. The subject matter exemplifies the challenges and possibilities of state and society being more responsive to one another in a time of crisis requiring **Solutions** (PART IV).

## [I]. NEED

2. DATA: A way to understand vaccination from the perspective of Disabled people is to start at a nominal end point. According to ONS figures, by March 2023 a higher proportion of adult Disabled people in England—regardless of the extent of impairment—had received a vaccine compared to non-disabled people.[1] This 2023 data indicates that Disabled people were, by then, able to take up the vaccine in substantial numbers.[2]

3. SITUATION: As with other aspects of the pandemic, there are problems with the data, particularly with how it was collected in real time (see §§25-30 below). But that overall result indicates that, despite barriers to accessibility, Disabled people by their actions expressed their need to be vaccinated. By September 2021 the Disability Unit ('DU') reported that "*attitudes to vaccination (e.g. vaccine hesitancy) are similar between disabled and non-disabled people*". However, Disabled people were "*more likely to have had their health care disrupted by the pandemic, and to report that this disruption [was] more likely to have resulted in a worsening of their health*".[3] Given risk to life and the impact of continuing lockdown, it was less open to Disabled people to be hesitant. Indeed, hesitancy as a concept can be used to individualise or to mask a problem which, properly analysed, concerns how society is organised and reveals that the greatest barrier to vaccination was accessibility.[4] For the DPO, the data shows that Disabled people acted in great numbers to overcome the social odds.

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[1] ONS Coronavirus and vaccination rates dataset 27.03.23 Table 1, Column K, Rows 36-39, cited in ONS Statistical bulletin [INQ000474605/11]

[2] Larson [INQ000474705/43 §97]. See also Kasstan-Dabush & Chantler [INQ000474623/66 §210]

[3] DU Presentation on Autumn Winter Planning 27.09.21 [INQ000083893/4]

[4] DPO M4 Opening [INQ000474794/3 §2.1] Mallick [T2/170/6-171/2] Waqar [INQ000485278/10 §31]

## [II]. TRUST

4. DISABILITY: The journey to that end position was not straightforward. Professor Heidi Larson distinguishes vaccine hesitancy from "vaccine confidence", as "*the trust individuals have in the importance, effectiveness, and safety of vaccines, as well as in the systems and institutions that deliver them*". Separately there are "*barriers to vaccinations…beyond an individual's control*" which can impact on trust arising from "*factors unrelated to vaccines themselves, such as structural discrimination and previous negative experiences with the healthcare system or authorities recommending vaccination*".[5] The description of potential challenges chimes with the definition of "disability" under Article 1 of the United Nations Convention on the Rights of Persons with Disabilities ('UNCRPD'), which arises from the "*interaction*" of an individual's long term impairment/condition with various barriers and attitudes that hinder their full and effective participation in society on an equal basis with others.

5. CONFIDENCE: The vaccination numbers by March 2023 were reached notwithstanding that Disabled people have grounds to mistrust aspects of health care. As Kamran Mallick framed it, "*We're often done to, we're often told that others know best…what's best for us, that we're not experts in our own lives and our own conditions that we live with day in, day out*".[6] With so much emphasis put on vaccines as the "*way out*" of the pandemic, Disabled people feared that the programme would not be designed for them.[7] For DPO it was foreseeable that Disabled people's needs would be overlooked in the delivery of vaccines. That bright line rules on prioritisation would be drawn up with Disabled people on the wrong side of them; competency and compliance in the field of reasonable adjustments would be assumed, and not properly monitored; and administrative systems would be set up to *do things to* Disabled people, rather than be in dialogue with and accountable to them. In the crisis of a pandemic, when there was no plan at the outset, and the state had to make hard choices and put in place mass systems, Disabled people had *good reason* to fear exclusion.

## [III]. ACCESS

6. MEANING: Access for Disabled people has a fundamentally more expansive and dramatic dimension than for people who spend most of their lives not having to think about it. Inadequate access is the ever-present basis for Disabled people's exclusion to operate and accumulate, and here it arose at the core stages of: DEVELOPMENT, PRIORITISATION, DELIVERY, ALTERNATIVES (for those who could not take a vaccine) and DAMAGE (for those who became dependent upon the Vaccine Damage Payment Scheme ('VDPS') due to harm caused). The DPO view 'access' as a "*whole complete planning system*" from development and the decision to vaccinate to booking

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[5] Larson [INQ000474705/6 §§2.1-2.2]
[6] Mallick [T2/171/10-17]
[7] Mallick [T2/171/17-23]

arrangements , location and the vaccination process itself.[8] The approach again coincides with Larson who emphasises that "*While vaccine confidence and practical access issues can be intertwined — with access often impacting vaccine hesitancy — it is important to identify specific practical barriers that can be addressed separately*".[9]

## [A]. DEVELOPMENT

7. RELEVANCE: Access issues arose at the point of vaccine and therapeutic development because there is a high rate of exclusion of Disabled people from biomedical research and the widespread use of ill-defined exclusion criteria in clinical trials, which is in keeping with a lack of diversity generally in the pre-authorisation stages of pharmaceutical innovation.[10] The consequences were relevant to coverage and confidence.

8. COVERAGE: Lack of diversity of Disabled people in clinical research, design and trials creates a structural risk to the pharmaceutical coverage of certain comorbidities, because participation is either low, or in the case of immunosuppressive conditions, often not appropriate and therefore dependent on post-authorisation observation and studies that generate less clinical evidence.[11] Conditions that affect a minority of people (however sizeable) and lie at the margins of tested vaccine efficacy and/or safety were therefore particularly vulnerable to political and market choices during the pandemic (see §§40-41 below).

9. CONFIDENCE: For all social groups who live with the knowledge that vaccines have *not been tested on people like them*, exclusion from the development stages of pharmaceuticals could affect confidence and also affect uptake.[12] The Vaccines Delivery Plan of January 2021 acknowledged that it was important to address individual concerns about how the vaccine fitted with individual circumstances such as a medical condition.[13] More generally, surveys published by Disability Equality Scotland in November 2020, just before the vaccine roll-out, found that some respondents' concerns related to the speed of vaccine approvals and whether all possible side-effects had been identified and considered.[14]

10. EXCLUSION: None of the DPO were asked to participate in testing, or feedback groups, during the development of vaccines and therapeutics before their approval. Neither were they engaged in the design of accessible communications about the relevant pharmaceutical options.[15] That was the case even though targeted communication was regarded as an essential condition of

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[8] Mallick [T2/171/21-23] [INQ000474256/11 §35] Rotenberg et al [INQ000417410/1]
[9] Larson [INQ000474705/7 §3]. See also Lamb [INQ000474350/42 §170]
[10] Camanni et al 'Being disabled' as an exclusion criterion for clinical trials: a scoping review. *BMJ Glob Health* (2023) 8(11) Larson [INQ000474705/41 §91] Knight [INQ000474611/28 §74]
[11] Evans & Prieto-Alhambra [INQ000474707/56 §§6.11-6.13] [T7/46/15-47/11] [T7/112/8-113/10]
[12] Mallick [INQ000474256/4 §§11-13]. See also Waqar [T3/7/2-8/20]
[13] Vaccines Delivery Plan 11.01.21 [INQ000399454/39 §5.25]
[14] Disability Equality Scotland [INQ000417433/2]. See also SG Report [INQ000376364/24-25]
[15] Mallick [INQ000474256/4 §§11-13]

effective delivery, and Disabled people's negative experience of health care was a foreseeable barrier to vaccine uptake.[16] Consequently, Disabled people had to make decisions whether to vaccinate at the point of roll-out with far less necessary information available to them than to non-disabled people (see §§32-36 below) and with even more limited knowledge about alternative options in terms of therapeutics and prophylactics, which for some Disabled people may have been the only viable option.[17]

11. INCLUSION: What was missing was impetus for clinical trial platforms to co-produce with organisations from underrepresented communities, ethical and trusted ways to source participants for trials, or observation studies, or any requirements on trial operators and research projects to consult and report on enrolment strategies.[18] Equally, as trials conducted under situations of emergency cannot always be representative,[19] excluded people and organisations should not just be asked to champion products after the trials have finished.[20] What was needed was integration of the right expertise and representative groups at the development stage, so that when vaccines emerged, such voices already had informed involvement and were in a position to explain what the vaccine, and any alternative options, entailed.

### [B]. PRIORITISATION

12. DISCRIMINATION: Prioritisation means unequal access.[21] In the first phase of scarce supplies and the need to make each dose count in its protective significance, it was necessary to discriminate.[22] Such predetermined categories or 'bright line rules' inescapably involve hard cases, but without general measures a system can become arbitrary as too much is left to individual judgement, institutional functioning, and geographical lottery.[23] The introduction of additional elements into prioritisation of vaccines meant the loss of simplicity, and for that reason the easiest prioritisation was age-ascending risk.[24] However, although age-ascending risk was rooted in evidence, there were always other compelling categories like the clinically extremely vulnerable ('CEV'), or indispensable care givers. The arguments for the prioritisation of these additional groups were also rooted in evidence, but the relevant considerations were not purely clinical, medical or scientific.[25]

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[16] Mallick [INQ000474256/4 §§12, 58-59] Scope Attitudes research 2022 [INQ000417429/4]

[17] Mallick [INQ000474610/9 §25]

[18] Larson [INQ000474705/41 §92] Deane [INQ000474511/91 §§276-277] Embedding Diversity in Research Design 20.06.23 [INQ000472225/2 §§2.1, 4.1]

[19] Technical Report 01.12.22 [INQ000087225/334] White [T12/16/1-6] [T12/39/20-40/6]

[20] Technical Report 01.12.22 [INQ000087225/333] Kasstan-Dabush & Chantler [INQ000474623/34 §107]

[21] PHE 18.11.20 COVID-19 vaccine and health inequalities [INQ000390037/3]

[22] Lim [T8/81/10-82/18]

[23] *Animal Defenders International v UK* (2013) 57 ECHR 21 §§106-110, *R (P) v SSHD* [2019] UKSC 3 §§48, 50, 55, 75-77]

[24] Kasstan-Dabush [T10/156/25-160/19]

[25] *Cf.* Swinson [T4/92/13-22]. On the social aspects of scientific/medical/expert advice, see DPO M4 Opening 13.12.24 [INQ000474794/3 §§2.2-2.5] DPO M2 Closing 15.02.24 [M2/INQ000399541/15 §§25-27]

13. VULNERABILITY: Outside of age, it was always accepted that there were categories of *medical* condition that put people under 65 acutely at risk of death from Covid, but the boundaries of the CEV list were based on incomplete and inaccurate understandings, and involved considerations that were not exclusively clinical.[26] CMOs accepted in Module 2 (as regards Down's syndrome) that there was a need to balance the nature of the clinical risk with the social imposition of lockdown.[27] There remained a broader tier of people classed as "*particularly high risk of severe morbidity and mortality from coronavirus*". However, medical risks are enhanced, or contained, by their synergy with socio-economic factors.[28] In the pandemic lexicon, the designation of 'clinical vulnerability' in fact combined clinical diagnosis *and* policy.

14. DISABILITY: The clinical term 'severe and profound learning disability' was contemplated by JCVI in a category of conditions referred to in the Green Book as 'chronic neurological disease', together with Down's syndrome and severe neurological disability.[29] However, the label 'severe and profound' was not always used by Disabled people, PHE had not used it in their own study of Covid fatalities,[30] and as Professor Wei Shen Lim accepted in hindsight, a person might simply not know that was a reference to them, or be described as such on a database.[31] The JCVI sub-committee meeting of 15 December 2020 acknowledged "*that the QCOVID analysis did not use severity gradings for learning disabilities because GP practice coding was not always graded*". That raised "*concern that incorrect or incomplete primary care records could mean that some individuals would be missed*", but the matter was characterised as "*an operational issue.*"[32] Investigation would have established that the definition 'severe/profound' was bound to have such operational consequences and so to strike against the essence of the JCVI aim to obviate risk.[33] Before that realisation happened in late February 2021, the JCVI advice was uncritically accepted by government, and not challenged by the Minister for Disabled People, who in December 2020 noted the PHE report and risks to those with learning disabilities, but said nothing about operational and data risks associated with the categorisation, and in January 2021 urged that there be no deviation from the current hierarchy of prioritisation.[34]

15. DEPENDENCY: Prioritising "*frontline*" care workers required understanding of the economics of the care sector, including its fragmentation, its lack of registration, and the fluidity of the

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[26] Mallick [T2/174/3-13] [INQ000474256/6 §§20-21] Letter to GPs 19.03.20 [M2INQ000048143/1]
[27] Whitty [M2/T24/132/17-133/1] [M2/T24/135/7-11] Harries [M2/INQ000273807/59 §§7.71,7.74-7.75, 7.80]
[28] Bambra & Marmot [M1/INQ000195843/75 §181] [M1/T/4/55/6-10]
[29] JCVI Advice 02.12.20 [INQ000354461/6]. *Cf.* Green Book Ch. 14a (Dec 20 version) [INQ000354471/9]
[30] PHE Review 12.11.20 [INQ000417384]
[31] Lim [T8/107/12-110/12] Mallick [INQ000474256/7 §23] [T2/176/8-18] Hancock [T3/93/20-95/20] [T3/96/17-20] Whately-Hancock WhatsApp exchange 13.02.21 16:25:37 [INQ000176785/36-7]
[32] JCVI Minute 15.12.20 [INQ000354465/5 §22]
[33] DPO M4 Opening [INQ000474794/8 §3.3]
[34] Tomlinson-JCVI 10.12.20 [INQ000083878] Ministerial Roundtable 04.01.21 [INQ000474832/1]

workforce,[35] especially the largely unregistered and only minimally supported situation of unpaid care givers.[36] The need to prioritise hospital and care workers was explained with reference to the risk of inadvertent spread of the virus within institutional settings. But outside of residential care, the failure to think through real world implications meant that the matrix of prioritisation excluded vaccinating those providing care in critical situations: e.g. housebound patients who could die for reasons other than Covid-19 infection without attendance,[37] and Disabled people living at home and requiring personal assistance for basic sustenance and mobility.[38]

16. PROCESS: Once decided upon, the potential for arbitrariness in the bright line categories became especially problematic. There were almost impossible hurdles to successful legal challenge.[39] The decisions were subject to minimal Parliamentary oversight, given the broad powers granted to the Minister to make regulations under Part 2A of the Public Health (Control of Disease) Act 1984 without the requirement of an affirmative resolution.[40] The decision to follow JCVI's 'scientific' advice unwaveringly was then made by the Secretary of State[41] in the erroneous belief that he was legally bound to follow the advice,[42] but defended in his evidence before the Inquiry that the matter "*wasn't an issue for my final decision, because I'd already decided that we should follow JCVI advice, whatever their advice was*".[43] With limited caveats, the Devolved Nations accepted the advice, even though Wales and Scotland would make changes to its implementation in due course.[44]

17. DISCRETION: In her oral evidence Clara Swinson, the civil servant with oversight of the policy, hypothesised an exception, of operational discretion for local vaccine providers to vaccinate an unpaid carer or a personal assistant at the same time as the person they were caring for.[45] Yet discretion to that end (unlike permission to offer vaccinations to avoid wastage) was never written into the Green Book or standard operating guidance, or communication to the public to enable

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[35] Kasstan-Dabush [T10/164/1-165/7] [INQ000474623/23 §60] CMOs/GSA Technical Report 01.12.22 [INQ00087225/296] Williams [INQ000485166/2 §5] Killian [INQ000474430/19 §§67-69] Abrahams [M2/INQ000281296/11 §§27, 39.1.1-39.3.1] [M2/T3/190/10-18] Harries [M2/INQ000273807/174 §§14.2-14.4] [M2/T28/38/4-15]

[36] Kasstan-Dabush & Chantler [INQ000474623/20 §§49-54] Mallick [INQ000474610/5 §§12-15]

[37] Russell [INQ000474228/51 §194]

[38] Campbell 14.01.21 [INQ000417404/3] cited by Mallick [INQ000474256/10 §§33-34]. See also Campbell 15.03.20 [M2/INQ000279964] Elder-Woodward [M2A/INQ000274175/1-5] CMEAG 12.02.21 [INQ000417388/1 §3] and also forthcoming Mallick [M6/INQ000520998/11 §§30-39]

[39] *R (Dolan) v SSHSC* [2020] EWCA Civ 1605 [§§86-90, 97] and the caselaw cited at footnote 23 above

[40] Health Protection (Vaccination) Regulations 2009 enacted without affirmative resolution (unlike in *Dolan*) by virtue of s. 45C and 45Q of Part 2A of the 1984 Act

[41] Hancock [INQ000474375/6 §§19-20] [T3/90/16-93/8]

[42] GLD-Bindmans Letter 01.12.21 [INQ000059575/4 §17] Summary Grounds of Defence 03.02.21 [INQ000110583/5 §§13-15, 18(b)-(c), 26, 29-31, 47, 58]. See also DHSC submission to SSHSC 30.11.20 [INQ000234199/4 §9]. *Cf.* Swinson [INQ000474334/30 §§103-104] [T4/75/10-24] Lim [T8/70/23-71/25]

[43] Hancock [T3/91/23-25]

[44] Drakeford [INQ000474420/18 §§64-65], E Morgan [INQ000474509/13 §35] Gething [INQ000493687/39 §§163, 229-230] O'Neill [INQ000474425/7 §§24-25] Swann [INQ000474451/7 §§23-24] Sturgeon [INQ000506900/9 §§36-37] Freeman [INQ000474452/11 §§45, 71-73]

[45] Swinson [T4/97/4-98/15] [T4/137/19-138/6]. *Cf.* Enhanced Service Specification [INQ000329490/12]

them to invoke the discretion.[46] In relation to carers, JCVI's minutes of 19 November 2020 had already registered that the system could not have such flexibility.[47] Ministers in Devolved Nations saw themselves as having "*operational flexibility*" based on devolved health care structures and definitions, including widening the definition of learning disability, but the same flexibility was not formally available in England,[48] and it hardly constitutes sound planning that Learning Disabled people were treated differently across the UK. There were rare examples of NHS Clinical Commissioning Groups that unilaterally amended Cohort 6 beyond the unreliable category of "*severe and profound*" before Government did, but it is not clear upon what legal basis this happened, or that regulations permitted general cohort re-arrangement in this way.[49]

18. ETHICS: Given the range of hard choices, which were not resolvable using a purely clinical calculus, it was axiomatic that ethical and broader social reflection was essential. Lord Bethell's evidence that there was no need for "*handholding by ethicists*" may be candid, but it overlooks that transparent integrated ethics analysis (as opposed to "*day-to-day conversations about…the vulnerable and health inequalities*") would have provided a procedural and substantive safeguard at the heart of the most difficult multifactorial and value-laden type of public service decision making.[50] Perhaps because Swinson knows that to be the case, she believed in her evidence that the Moral and Ethical Advisory Group ('MEAG') "*carefully considered*" the issues on the different cohorts,[51] whereas records of MEAG make clear that prioritisation was discussed in May 2020, and then not until March 2021.[52] The upshot is that beyond other witnesses' assurances that *they felt they were* acting ethically, evidence of ethical decision-making on phase 1 vaccine prioritisation is largely limited to the mere existence of MEAG and the presence of a single non-voting member of JCVI.[53]

19. MISUNDERSTANDING: The reality is that MEAG was marginal. Its own efforts to develop and publish an ethical framework were met with resistance.[54] Its attempts to engage discussions with the rest of UK government did not take off;[55] just as interventions by the Nuffield Council on Bioethics to prompt a greater role for ethics in general and for MEAG in particular were ignored.[56] To the extent that Welsh government was more orientated to social partnership and (for Disabled

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[46] Swinson [T4/99/10-19]. *Cf.* Ramsay [T6/100/22-101/1] (Green Book "*reflects policy decisions that have been made on the basis of JCVI recommendations*") Swinson [INQ000474334/35 §119]
[47] JCVI Minute 19.11.20 [INQ000354456/4 §17]
[48] Strath [INQ000474447/45 §184] Gething [INQ000493687/53 §231]
[49] Kasstan-Dabush & Chantler [INQ000474623/93 §304] Mallick [INQ000474256/8 §27] NHS Kent and Medway [INQ000417394/8] NHS Leicester [INQ000414459/16]
[50] Bethell [T11/66/1-67/15] Bethell [INQ000474434/27 §80]
[51] Swinson [T4/94/16-95/15]. *Cf.* Swinson [INQ00047334/31 §§111(a), 198] (only refers to MEAG 13.05.20)
[52] Montgomery [INQ000474339/9 §§33, 40-41, 45] MEAG 13.05.20 [INQ000401387] MEAG 03.03.21 [INQ000496176]. See also MEAG 18.11.20 [INQ000193133/2-3] (reference only to "*short discussion*")
[53] Lim [INQ000471988/13 §§42(iii), 74] (a non-voting ethics expert was co-opted at sub-committee level)
[54] Montgomery [INQ000474339/6 §22] Email PS Bethell to PS Hancock 19.05.20 [INQ000486316]
[55] MEAG 09.09.2020 [INQ000401398] Montgomery [INQ000474339/19 §§62, 64]
[56] Hamm [INQ000474245/6 §§19-26, 35, 43-44, 47]

people) social model-based policy making, the Welsh CMEAG, with Disability Wales as a DPO member, gave advice on vaccination issues for people with learning disabilities and carers, whereas MEAG did not (see further §§32-33 below).[57] The heart of the problem was a misunderstanding of what ethics is: *not the imposition of values*, or a form of politics,[58] but a systematic, structured and transparent approach that assists decision makers to make hard choices and elaborate the values at stake.[59] Others narrowly confined the role of ethics to the circumstances of "*very scarce resources*" if ICUs got overwhelmed, or vaccines "*running out*".[60] Consequently, the JCVI's categories based on age, institutional workers, and clinically extreme vulnerability were wrongly treated as outside the scope of applied ethics, and mistakenly regarded as clinically neutral matters without social content.

20. CARE: It was obvious, too, that prioritisation decisions needed the input of social care and other specialists, with the benefit of dialogue with representative groups, including DPO. That was not least because JCVI was making decisions relating to social care, when none of its members were a specialist in the area,[61] and the specialism had myriad implications for delivery in terms of definition, identification and four nation variation.[62] In setting out to prioritise "*those most at risk and those who work closest with them*",[63] the question of whether "*frontline social care*" should exclude domiciliary care again required non-clinical considerations because of its implication for care receivers with life sustaining needs. The JCVI sub-committee minutes indicate that "*household carers*" were originally going to be in Cohort 2, but on 19 November 2020 it was suggested that they would be moved to "*alongside the moderate…at-risk group, after those aged 65-70 years*" (i.e. Cohort 6), because of "*the difference between people working in a residential care home and household/live-in carers was the number of people to whom they would be exposed*".[64] The JCVI carried out no in-depth analysis of what that would mean for those acutely dependent upon household care.

21. DEFINITIONS: Even in Cohort 6, the way eligible carers were defined in the Green Book and by a footnoted reference in published guidance was "*unacceptable*" in terms of its lack of accessibility and because it misunderstood the lives of Disabled people.[65] Once the Green Book was reached by a lay person, if it ever was, they discovered that PHE had narrowed the definition from "*main*" carer in November 2020 to "*sole or primary*" carer in February 2021. Matt Hancock had feared

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[57] Payne [INQ000507523/6 §§51, 53-57] Mallick [INQ000474256/23 §76]
[58] Bethell [INQ000474434/31 §86] Parker [INQ000056579/13 §§6.8-6.9]
[59] Parker [INQ000056579/15-16 §§7.6-7.12] (for an outline of what ethics is and what it is not) Parker [INQ000271874/21-22] and [INQ000056579/17 §7.19]
[60] Van Tam [T5/187/16-188/7]
[61] Whately [M2/INQ000273897/70 §§315-316] Email Correspondence 16.11.20 [M2/INQ000328014/1-2]
[62] DPO M4 Opening [INQ000474794/5 §2.5]
[63] Zahawi Paper 25.01.21 [INQ000092297/1]
[64] JCVI sub-committee 19.11.20 [INQ000354456/4 §16]
[65] Mallick [T2/178/12-181/17] [INQ000474610/3 §§4-8]

that this would lead to false claims, but Scottish and Welsh evidence was that this was not the case.[66] The PHE evidence was that narrowing the definition was never intended,[67] although the Welsh Government interpreted the word "*primary*" to mean no more than "*two*" either because some activities required two people such as "*positioning, hoisting, bathing and changing*" or because there "*may be arrangements whereby two people evenly divide the caring responsibilities*": but what if there were four?[68] In the reality of Disabled people's lives, a person may have one or more carers, and may not live with them. As recognised in Scotland, where under the Carers (Scotland) Act 2016 a 'carer' is an individual who provides or intends to provide care for another individual, the concept extended to "*carers whom people rely on for day-to-day in-person support*", such that "*access to the COVID-19 vaccination [was] not limited to only one carer in a caring relationship*".[69]

22. PLANNING: Combined with the barriers to defining carers' eligibility was the systemic inability to identify them. Unpaid carers were not automatically listed on GP records and there was no national register of personal assistants. Only in January and February 2021 did the UK Government seek assistance from the DWP by reference to carer's allowance payments, which in turn were not regarded as fully reliable or complete.[70] The DHSC did not issue a Standard Operating Procedure ('SOP') until 8 March 2021, more than three weeks after carers became eligible for a Cohort 6 vaccine.[71] The situation was particularly acute in Northern Ireland where 12% of the population are involved in caregiving, with no register and no reliable means to identify and contact vaccine eligible candidates.[72] Although Northern Ireland opened up the category to self-identification by reference to the published criteria from 17 February 2021, this was delayed in the other nations to 8 March in Wales, 15 March in Scotland, and 17 March in England.[73] The problems extended to personal assistants, whom the Government's vaccine plan described as "*vital*" to reach as part of Cohort 2, but there was no clear basis to do so.[74]

23. CONSEQUENCES: The JCVI was not directly concerned with delivery, but the absence of ethical analysis and broader social advice exposed the JCVI's approach to mistaken assumptions

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[66] Hancock Diaries [INQ000474704/81] Hancock WhatsApp 15.02.21 2:41 PM [M2/INQ000095756/2] NAO 25.02.22 [INQ000065228/60 §3.24]. *Cf.* Richardson [T10/95/13-96/25] Lamb [INQ000474350/50 §197]

[67] Ramsay [T6/99/14-103/7] Lim [T8/110/13-111/10] [T8/117/20-119/11]

[68] WG Guidance 24.02.21 [INQ000492866/5]

[69] Mallick [INQ000474610/4 §11] [INQ000474574/1]

[70] On unpaid carers: Lawson [INQ000492335/56 §§178, 212, 339(b), 341(e)] Couling [INQ000474736/8 §§3.1, 4.2] Email DWP 5.2.21 [INQ000474708/13-14] Email DHSC 22.1.21 [INQ000528565] Mallick [INQ000474610/5 §§12-15] On Personal Assistants: C Williams [INQ000485166/9 §§18, 26] Social Care Vaccines Stakeholder Group 29.1.21 [INQ000397403] Mallick [INQ000474256/10 §34]

[71] SOP – unpaid carers (JCVI priority Cohort 6) 08.03.21 [INQ000329462] DHSC 15.02.21 [INQ000234751]

[72] Kasstan-Dabush & Chantler [INQ000474623/21 §51] Chada WhatsApp 22.02.21 [INQ000477804/22]

[73] Mallick [INQ000474610/5 §§13-14]: see NI Press Release 17.02.21 [INQ000474571] WG Guidance 24.02.21 [INQ000492866] WG Press Release 08.03.21 [INQ000474578] SG Press Release 15.03.21 [INQ000474579] Carer's UK Article 17.03.21 [INQ000474577] NHS Guidance 01.04.21 [INQ000377485/5]

[74] Swinson [T4/137/19-138/6] Vaccines Delivery Plan 11.01.21 [INQ000399454/38]

which, in turn, impeded delivery of the vaccine to those with learning disabilities and carers. With the benefit of earlier engagement with disability specialists and DPO, the clinical purism about learning disability could have been realised and unconsidered aspects of employed and unpaid domiciliary care addressed.[75] Chris Whitty's evidence was that JCVI independence was "*absolutely critical*" but "*that doesn't mean they should not hear what government is doing [and] understand what's happening in other parts of the system*".[76] JCVI Covid-19 vaccination advice is a case study on how that could have been done better.

## [C]. DELIVERY

24. SYSTEM: On delivery of vaccines the DPO urge caution about the summary position put to Dame Emily Lawson, which she agreed with, that vaccination centres operated in accordance with standing procedures that ensured that they were at least "*systemically*" accessible to Disabled people.[77] As a summary position that is not correct. It does not match with the accounts across the country that DPO and the Inquiry has received.[78] It assumes too readily that accessibility was adequately addressed. The following system problems suggest that the national organisations with oversight of the vaccine roll-out leaned too heavily on such assumptions.

25. DATA: Despite the 2023 ONS findings of how things turned out *in the end* (see §2 above), Disabled people were more likely to be unvaccinated in the earlier period. Concern was highlighted by the DU in March 2021, citing research that a lower percentage of Disabled people over 70 had been vaccinated than non-disabled people. The difference was of 1.52 x greater likelihood to be unvaccinated, if 'limited a lot' in terms of impairment, and 1.17 if limited a little.[79] Initial studies by OpenSAFELY identified comparatively low rates amongst those with severe mental illness (30.3%) and learning disability (28.1%).[80] The deeper problem was that the ONS figures could be no more than "*estimates for vaccine coverage by…disability status*".[81] Its assessments at the initial stage rested on linking data from different (mostly NHS) and often incomplete databases with near decade-old Census returns that lacked disaggregation based on impairment type, which in the DU's view "*preclude[d] their incorporation into vaccine coverage monitoring*".[82]

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[75] Swinson [T4/97/4-25] [T4/100/3-101/23]
[76] Whitty [T5/97/7-10]
[77] Lawson [T9/184/2-185/8]
[78] DPO M4 Opening 13.12.24 [INQ000474794/11 §§5.1-5.6] Mallick [INQ000474256/11 §§36-49] Kasstan-Dabush & Chantler [INQ000474623/80 §§265-266, 273] ESM [INQ000474465/41]
[79] DU Deep Dive 31.03.21 [INQ000083885/4, 6, 10, 27, 36] ONS bulletin 20.01.22 [INQ000474600/8]
[80] OpenSAFELY 27.01.21 [INQ000417440/2, 9-10]
[81] Diamond [INQ000474591/21-22 §§72,74]
[82] DU Deep Dive 31.03.21 [INQ000083885/6] Mallick [INQ000474256/19 §61] Kasstan-Dabush & Chantler [INQ000474623/66 §210]

26. FORESIGHT: Going into the pandemic the data infrastructure to target prioritised groups and monitor their uptake was unfit for purpose.[83] All four nations were in the same position.[84] The exposure of Disabled people in terms of equitable health care had been criticised by the UNCRPD Committee.[85] The DU had questioned the reliability of data throughout the crisis[86] and, in their invited "*ambitious*" reform package of November 2020, proposed a Data Commission to improve capacity to "*breakdown of types of impairment*" and greater capacity in "*monitoring of policies to assess effectiveness*".[87] PHE and NHS England knew that their data on protected characteristics was "*variably collected*" and that a 2019 national immunisation equity audit had established that "*no assessment could be made on adults with learning disability, children or adults with physical disability, mental illness or chronic physical illness*" (and other at risk groups) "*due to lack of systematically collected data*".[88]

27. PATCHWORK: The system resorted to the inevitable patchwork solutions. GPs were directed to begin "*by no later than 1 September*" 2020 to start "*to ensure that datasets are complete and timely*" for people with protected characteristics,[89] and to "*proactively engage*" with those with poor health outcomes "*to ensure that everyone with a learning disability is identified on their register and that annual checks are completed*". The aim was to update on 67% of the patient body by 31 March 2021.[90] This was belated and unrealistic given the vaccine roll-out would begin in December, and patient groups, especially Learning Disabled people, were known to have markedly diminished contact with primary care since the pandemic began.[91]

28. MONITORING: In real time the system did not know how accessible it was. The newly commissioned National Immunisation Management System ('NIMS'), which was used to provide data on the vaccine programme to government, national and local health agencies,[92] did not record disaggregated data on disability at the point of vaccination.[93] The position was the same with the Scottish Vaccine Management Tool and the Northern Irish Vaccine Management System.[94] Accurate and timely "*visibility on uptake*" was lacking.[95] Awareness of whether the

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[83] Marmot [M1/T4/68/22-69/10] [M1/T4/70/18-71/8] Sudlow Review (2024) [INQ000513700/15, 27, 56]

[84] DPO M2 Closing 15.01.24 [INQ000399541/23 §35] DPO M2A Closing 23.02.24 [§§23-24] DPO M2B Closing 05.04.24 [§13] DPO M2C Closing 06.06.24 [§29]

[85] UNCRPD Art. 31 and UNCRPD UK Country Report (2017) [M2/INQ000182691/10 §§64-65]

[86] DPO M2 Opening 26.10.23 [§3.8] DPO M2 Closing 15.01.24 [INQ000399541/24 §§36-37]: see especially Bell [M2/INQ000198850/26 §62]

[87] Covid O DU Submission 12.11.20 [M2/INQ000083918/1 §3.1, §5 and Annex A pp 2-4] DPO M4 Opening 13.12.24 [INQ000474794/2 §1.2]

[88] PHE 06.01.21 COVID-19 vaccine and health inequalities [INQ000390037/9-10] Ramsay [INQ000496177/30 §§6.13, 6.17, 7.2-7.3] Lawson [T9/167/14-168/13]

[89] Lawson [T9/168/13-169/21] referring to [INQ000180768/10-11]

[90] Implementing Phase 3 of NHS Response to Covid-19 07.08.20 [INQ000180768/7-8]

[91] For less contact 2020/21, see Health Inequalities Urgent Actions Update 30.11.20 [INQ000414404/5]

[92] Russell [INQ000474228/19 §§89, 332(a)] Lawson 25.01.21 [INQ000414427/3 §13]

[93] Russell [INQ000474228/156 §568] Killian [INQ000474430/12 §42] Lawson [T9/208/16-25]

[94] Phin [INQ000474427/42 §160, 298] McBride [INQ000474249/8 §20] Chada [INQ000474476/25 §§99, 158, 162-163] (disability especially under monitored) [T10/127/23-129/18]

[95] NHSE paper 28.01.21 [INQ000414427/3 §13]

delivery programme was reaching those who needed it, and what additional service warranted commissioning, was absent at the local level.[96] The deficit was part of a broader problem with NIMS that its capacity to register whether a person was CEV was dependent on the condition being registered in an NHS record, and the person otherwise having an NHS number, which had implications, amongst other things, for whether they received notifications for second vaccines.[97]

29. DESIGN: This was classic system error. The specification to track disability was left out of the design of technology developed by NHS England in conjunction with consultants that (as above) government and wider health care systems knew was lacking in other records, and which the disciplines of disability rights and disaster risk management regard as fundamental.[98] The DU and the Minister for Disabled People were apparently not involved in developing NIMS, nor co-opted into correcting the issue once identified, with the focus on BAME, a factor that NIMS did capture, and not disability, which it did not.[99] Therefore, Ministers and other advocates of the vaccine success narrative point glowingly to a piece of technology that was not inclusive in its design, which DPO were not consulted on, and which could not achieve real time monitoring of Disabled people's uptake.[100] The DU admitted in September 2021 that vaccination data based on "*specific health conditions*" did "*not adequately cover the breadth of disability by Equality Act 2010 definition*".[101]

30. CONSEQUENCES: The outcome was that the system had no real idea how it was doing on accessibility for Disabled people and whether it was a success. In fact, the slower initial uptake and results from the ONS Opinions and Lifestyle Surveys in 2021 indicate that a greater proportion of Disabled people anticipated difficulties when going to get a vaccine and had experienced such difficulties, and that the figures did not markedly differ between first and second doses.[102] More broadly, an opportunity was lost to capture and monitor critical aspects of health equity and human geography across the UK at a point when health systems encountered millions of people in a short space of time.

31. EQUALITY: The Vaccine Equalities Committee ('VEC') that was created in January 2021 did not consider Disabled people's access to vaccines, including those with learning disabilities.[103] It

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[96] Killian [INQ000474430/12 §§42, 50]

[97] Tessier et al 23.12.22 [INQ000477127/2 §§2.1(a), 4.1] DR UK 05.07.21 [INQ00023853] (letter to UK Government noting that 2/3 of CEV individuals yet to be double jabbed)

[98] DPO M2 Opening 26.10.23 [§§2.7-2.9]: see esp. UNCRPD Art. 31, WHO World Disability Report (2011 Rec. 8 p. 267) The Sendai Framework for Disaster Risk Reduction 2015-2030 19(g)

[99] Tomlinson [INQ000474588/10 §29]

[100] Zahawi [T9/123/5-11] Ramsay [T6/104/8-105/5] [INQ000496177/30 §6.14] Russell [INQ000474228/93 332(a)] *Cf.* Mallick [T2/185/16-186/13] Larson [INQ000474705/66 §178] Chantler [T10/154/7-24]

[101] DU Presentation on Autumn Winter Planning 27.09.21 [INQ000083893/4]

[102] ONS OLS Surveys Mar-Apr 21 [INQ000474764/18 Table 16 col AX-BD] Apr-May 21 [INQ000474765/13 Table 11 col Z-AF] May-Jun 21 [INQ000474766/13 Table 10 col Z-AF] Jun-Jul 2021 [INQ000474737/21 Table 17 col Z-AF]

[103] Vaccines Delivery Plan 13.01.21 [INQ000399454/39] Vaccine Uptake Plan 13.02.21 [INQ000087230/6] TOR 04.02.21 [INQ000502101/3]

had no disability focused membership.[104] The Equality Hub only sent personnel from the Race Disparity Unit.[105] In his witness statement the Minister for Disabled People does not mention the VEC at all, let alone in relation to accessibility.[106] Despite all the problems with data collection, including the incapacity to be reliably assured about Disabled people's vaccine uptake, the Vaccine Equalities Tool did not record disability status.[107] As with Minister Badenoch's thematic review of disparities, the VEC slanted heavily to the disproportionate impact on ethnic minority communities which in Badenoch's words were "*in the news*" and so determined the "*political salience*",[108] while Disabled people were left out of the remit.[109]

32. Engagement: No aspect of the UK vaccine programme was designed with DPO. DPO were not included in the VEC. DPO were not methodically enrolled into a "*strategic community engagement*" at local/regional and national level to enable the improvement and tailoring of services.[110] The disconnect between government's notion of engagement as discretionary and ad hoc, rather than systematic, rights based and institutional,[111] is exemplified by the Ministerial Roundtable on vaccines in January 2021, when it was said that there was "*extensive engagement with DWP disability stakeholder groups — i.e. Disability Charities Consortium — who are responsive groups and trusted voices*" to whom Ministers could "*feed information*".[112] It had not been extensive, but in any event, engagement was expressly treated as an opportunity to communicate information about the vaccine, as opposed to enrolling charities or DPO into co-design of the roll-out.[113]

33. Devolved Nations: By contrast, the Welsh Vaccine Equity Committee ('WVEC') had representation and input from DPO, which was reflected in specific work directed towards Disabled people,[114] all of which ran in tandem with the continuous sitting of the Disability Equality Forum (chaired by the Deputy First Minister[115]) and CMEAG (see §19 above). DPO were also involved directly in the Scottish National Vaccination Inclusion Group ('VIG') that specifically included "*practical and physical barriers and access to digital technology*" within its remit.[116] In

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[104] ANNEX 1 membership 04.02.21 [INQ000502101/5-6] and ANNEX 1 (Version 5) 27.07.21 [INQ000468693/6] (by which time it had one civil servant focussing on "*mental health and learning disability*")
[105] Bell [M2/INQ000198850/64 §150]
[106] Tomlinson [INQ000474588]
[107] Russell [INQ000474228/25 §114] Lawson [INQ000492335/49 §158]
[108] Badenoch [T9/38/21-39/2]
[109] Badenoch [T9/73/11-74/2] DPO M2 Closing 15.01.24 [INQ000399541 §24] Banfield [INQ000474589 §235]
[110] Chantler [T10/176/9-177/14] DPO M4 Opening [INQ000474794 §2.6] Mallick [INQ000474256 §§68-71, 79]
[111] DPO M2 Closing 15.01.24 [INQ000399541/21 §§32-34] DPO M2B Closing 05.04.24 [§§27-30]
[112] Ministerial Roundtable 4.1.21 [INQ000474832/1]
[113] DPO M4 Opening [INQ000474794/5 §2.7]
[114] Vaccine Equity Committee TOR 18.03.21 [INQ000182550/4] Mallick [INQ000474256/23 §§74-76] Richardson [INQ000501330/52 §231]
[115] DEF 21.10.20 [INQ000353422/6 §4.9] DEF 27.01.21 [INQ000282063/3 §2.8]
[116] Vaccine Deployment Plan 26.03.21 [INQ000376301/12] VIG Briefing 15.03.21 [INQ000501276/1] VIG Minute 15.03.21 [INQ000501277/2-3] VIG Minute 07.04.21 [INQ000501280/2-3] Mallick [INQ00474256/22 §§72-73] Grieve INQ000474396/36 §87] Lamb [INQ000474350/47 §§187, 193-194]

Northern Ireland there was no engagement or consultation between the Northern Ireland Executive and DPO regarding the vaccination or therapeutic programmes.[117]

34. Procedures: The SOPs for vaccine centres were woefully minimalist about Disabled people. In the original versions, under the heading 'Access' there was no guidance on physical access and environmental issues, nor reference to the NHS Accessible Information Standard ('AIS'), with the bare suggestion that supporting literature in easy read formats "*may be helpful*".[118] After several versions, the SOPs were finally amended to include a section on "*Communicating for diversity and inclusion*" referring to a number of resources and to people with learning disabilities and autistic people, but there was still no reference to Braille or to the AIS.[119] The amended document said nothing more about physical and environmental accessibility at and within vaccination centres.

35. Communications: Compliance with the AIS, which the NHS regards as a mandatory legal requirement, is a chronic problem in UK health services.[120] Professor Powis conceded in Module 3 that compliance with the standard was managed "*on a sporadic basis*" and that the extent to which it was followed and applied was "*variable*".[121] Despite Minister Tomlinson having drawn accessible communications to the attention of Minister Zahawi in December 2020, the deficit quickly became "*a very common theme in engagement*" involving "*calls for accessible communications about all aspects of the vaccination programme – from safety information for each vaccine to information about where to go for local vaccination to allow disabled people to make informed choices*".[122] Eight months later the DU emphasised that accessible communications were still a "*stakeholder concern*".[123] The CEO of the RNIB Matt Stringer said that "*little if any regard*" was had for the AIS, [124] a point underscored by the fact that NHS England only *planned* to send letters in Braille for a first vaccine dose to those who had not received it in July 2022, more than 18 months after the roll-out began.[125]

36. Barriers: The structural failure to correct the problem led to practices described by the DPO of letters to blind people, telephone calls to d/Deaf people and the use of the internet and smart phones as the primary means of making vaccination 'convenient', resources which vast parts of

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[117] Mallick [INQ000474256/23 §77] DANI 03.02.22 [M2/INQ000396851/14]. See also DPO M2C Closing 06.06.24 [§§16, 20-21, 24, 32, 37]

[118] SOP Version 2 18.12.20 [INQ000329393/8]. See also SOP Version 3, 4.01.21 [INQ000329413/7] (no change) SOP Version 3.2 14.01.21 [INQ000329429/8 (no change)

[119] SOP Version 3.3 08.03.21 [INQ000329465/32]

[120] NHS England 08.10.17 [INQ000417405/11 §4.1] Mallick [INQ000474256/11 §36] Richardson [INQ000501330/52 §231] Goddall [INQ000499055/55 §161]: see WVEC Minutes 22.03.21 [INQ000429186/2] (unpaid carers and learning disabilities) and Briefing [INQ000492853/3] (accessibility at vaccine centres)

[121] Powis [M3/INQ000485652/73 §§277-278]

[122] Tomlinson-Zahawi 15.12.20 [INQ0004994931/1] Zahawi [INQ000474307/55 §146] Draft COVID-O "Vaccine Update" paper 25.01.21 [INQ000499499/6]

[123] DU Presentation on Autumn Winter Planning 27.9.21 [INQ000083893/13]

[124] Stringer [M3/INQ000235594/6 §13]

[125] Fothergill [M2/INQ000114206/13 §39]

the Disabled population do not have access to.[126] Government, NHS England and others knew that communication needs existed well in advance of the delivery programme, but did not design solutions into the original procedures for notifying eligibility, booking arrangements and centre management.[127] With regard to digital exclusion, the Public Sector Implementation Group realised the problem in May 2020.[128] As of 30 November 2020, the NHS 6th Urgent Action update on Health Inequalities recorded that digital inclusion as an aim was not yet rated in terms of progress, due to lack of time to fully assess the subject, "*but stakeholders [were] flagging up real concerns*" that given the "*importance of and sensitivity*" of the Covid vaccination programme presented "*an inherent risk*".[129]

37. ASSUMPTIONS: The above system problems had in common an assumption that vaccines were "*the bread and butter of the NHS*",[130] as Lawson put it, or as Swinson framed it in her statement "*DHSC and wider health systems had sufficient institutional knowledge and experience of vaccine programmes*" with "*practices, procedures and approaches to communication, uptake and safety*" already in place, which could be operationally leaned into, when the time came.[131] In conflict with these beliefs, the Inquiry has evidence of the exercise at Epsom racecourse in October 2020 that, according to Dame Emily's statement, formed the test of the "*pod model*" for vaccination centres.[132] The exercise identified that "*policy around disability needed to be clear and form part [of] a cross-cutting patient experience*". It recommended planning "*involving staff training, model design, booking arrangements and all communications*".[133] The template for the SOPs in November, informed by this very exercise, did not mention the recommendation.[134] It did not form a part of any of the subsequent SOPs (see §34 above).

38. EXCEPTIONS: Innovations on accessibility based on partnership with local communities were exceptions not the norm.[135] For instance, specialised, low sensory clinics to vaccinate Learning Disabled people were initiatives local to Leicester and Great Yarmouth;[136] there is no evidence that they were taken up as national best practice, and they were only cited several months into

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[126] DPO M4 Opening 13.12.24 [INQ000474794/12 §§5.3-5.4] Mallick [T2/174/20-175/8] [T2/183/10-21] [INQ000474256/11 §§37-40]
[127] DPO M4 Opening 13.12.24 [INQ000474794/12 §§5.4-5.5]
[128] GPSMIG 8.4.20 [M2/INQ000177567/16 §26(4) and 27(iii)] Annex A [M2/INQ000083403/9]. See also Mallick [INQ000474256/12 §41] Watson & Shakespeare [INQ000280067/8 §§25-26] [M2/T5/35/16-40/8] UK Consumer Digital Index 2019 [INQ000489462/10, 15]
[129] Inequalities Urgent Actions Update 30.11.20 [INQ000414404/2]
[130] Lawson [T9/137/16-17]
[131] Swinson [INQ000474333/2 §7]
[132] Lawson [INQ000492335/8 §26(b)]
[133] NHS Exercise Asclepius 12.10.20-13.10.20 [INQ000113288/17]
[134] SOP v2 11.12.20 [INQ000438433]
[135] Rotenberg et al [INQ000417410/1] Mallick [INQ00047456/14 §45] Kasstan-Dabush & Chantler [INQ000474623/92 §§302-304]
[136] NHS Leicester 15.07.21 [INQ000414459/16-19] Whitehouse et al [INQ000417413]. See also in Wales Richardson [T10/93/20-94/7]

the roll-out.[137] The corporate statement of NHS England indicates its relevant lessons learned for Disabled people during the programme to include "*the importance of making reasonable adjustments for individuals throughout all stages of an individual being vaccinated, from information being provided in advance through to the experience of accessing a vaccination site*"; "*proactive collaboration with multiple partners*", which could include DPO although it does not say as such; "*creating a comprehensive list of carers of vulnerable housebound patients was a significant challenge*" and overcoming elements of data collection "*given the starting position of data pre-pandemic*" and that much of the data capability required had to be built "*from scratch*".[138]

39. CHANGE: The current NHS vaccination strategy aims for services better tailored to local communities that need to be "*supplemented by bespoke, targeted outreach interventions for specific populations currently underserved by vaccination services*".[139] It also seeks to "*build on the partnerships with underserved communities developed during the COVID-19 pandemic to ensure communication strategies are informed by community insight*".[140] The focus is on communities of faith and racial and ethnic minorities, who no doubt require it, but not on Disabled people, who do also. It therefore reads as a strategy orientated to improving uptake, rather than to improving accessibility, which is essential of itself but also because of the interrelationship between accessibility and hesitancy.[141] The strategy lacks a dedicated action plan to achieve "*long-term engagement*", which cannot be built up quickly but needs time and dedicated initiative, method, practice and organisation.[142]

### [D]. ALTERNATIVES

40. EXCLUSION: The UK did not generate a therapeutics and prophylactics response to Covid with the same success that it did with vaccines.[143] The accounts of Ministers, advisers and civil servants, and the competing positions based on priorities, costs, and available clinical evidence have been heard.[144] What is missing, because there was no role given to it, is ethical and social analysis. It should be striking to everyone, as it was to Dame Kate Bingham, that moral and ethical values were at stake,[145] but those values were never explained or justified because ethical analysis in relation to this matter, like prioritisation, was not integrated into decision

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[137] Lawson [INQ000492335/58 §188(b), 188(c) and 189 (only publicising Leicester initiative in July 2021)

[138] Russell [INQ000474228/166 §§619-20, 623]

[139] NHS England Shaping the Future Delivery of NHS Vaccination Services (Dec 23) [T13/35/9-14] p. 25 §3.1.10 and p. 31 (case study of a tailored service for people with learning disability in Liverpool)

[140] Shaping the Future Delivery p.11 and §3.2.15

[141] Larson [INQ000474705/7 §3]

[142] Kasstan-Dabush & Chantler [INQ000474623/35 §112]. See also Javid [T8/33/17-35/17]

[143] Bingham [T6/12/4-7] Gabbay [INQ000474400/13 §§34, 47, 74] Knight [INQ000474611/58 §144]

[144] Hancock [T3/86/9-90/15] Sharma [T4/37/21-42/12] Swinson [T4/131/25-134/7] Little [T4/161/12-165/21] [T4/144/10-145/7] [INQ000474557/47 §§177-197] Whitty [T5/113/5-116/14] Vam Tam [T5/175/23-182/23] Bingham [T6/49/16-51/8] [T6/52/11-21] Javid [T8/39/16-42/11] [42/12-46/18] [48/25-50/11] [51/10-52/3]

[145] Bingham [T6/49/16-25]

making.[146] The result is that more than a million clinically vulnerable people are excluded from the national solution to Covid,[147] but without any of the support systems that may have been available to them during the height of the pandemic.[148] The clinical, cost and ethical analysis of what is to be done remains incomplete.

41. Social Model: For reasons regarding pharmaceutical development in general (see §§7-11 above) it would be wrong to reduce this discrepancy between Covid vaccines and their 'alternatives' to a purely clinical explanation. The nature of immunosuppressed conditions limited the feasibility of participation in clinical trials for reasons of safety, which made assessment of efficacy more dependent on lab research and observational studies.[149] Without embedded diversity in pharmaceutical design and research the available methods generated less data in volume and depth on the value of products like Evusheld (as a monoclonal antibody) when compared to mass clinical trials and global post-authorisation surveillance of vaccines.[150] The product was consequently under-assessed.[151] Cost could fairly be described as not the single determining factor.[152] Yet underassessment injected comparatively greater uncertainty at the crucial point in time for deciding to purchase drugs that were far more expensive *per capita* than vaccines and for smaller numbers of users.[153] Once it became apparent that there was a good vaccine with high efficacy, and that effective antivirals were slow to be developed, the perceived importance of prophylactic drugs receded.[154] Overall, if antivirals became the lower prioritised 'other' to vaccines – its "*second class citizen*"[155] – the social model is relevant to what happened here. The evidence indicates that decision-making did not sufficiently consider the foreseeable implications of the structure of the pharmaceutical industry and the risk that prophylactic drugs, in particular, could get left behind.

42. Change: It does not have to be like this. Trials and observations can be more tailored to communities, including offsite and virtual studies for immunosuppressed patients rather than requiring them to attend a trial site.[156] Alternative funding packages can be negotiated, including

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[146] Montgomery [INQ000474339/10 §35]

[147] APPG report, *Forsaken But Engaged* (2023) [INQ000417415/2] Little [INQ000474557/53 §200] Bingham [INQ000474406/43 §38.11-15] [T6/52/11-21] Bethell [T11/60/14-61/6]

[148] Mallick [T2/187/10-18]

[149] White [INQ000474743/24 §3.35]: see Evans & Prieto-Alhambra fn. 11 above

[150] White [T12/22/15-23/12] Knight [INQ000474611/53 §§128-129, 133]

[151] White [INQ000474743/72 §§6.15-6.16] Knight INQ000474611 §136] Bingham [INQ000474406/42 §38.6] [T12/61/6-63/6]

[152] Taylor [INQ000474273/18 §80] Whitty [INQ000474401/80 §7.25] [INQ000507423] Knight [T12/66/15-67/18] *Cf.* Bingham [T6/52/1-21]

[153] Bingham [INQ000474406/42 §38.6] Dix [INQ000474423/18 §§9.1-2] Dix [T12/87/14-89/22] [T12/90/1-91/7]. See also Bethell [T11/63/13-65/11]

[154] Whitty [INQ000474401/80 §7.25] Gray [T11/89/20-91/5]

[155] Bingham [T6/21/20-24]

[156] DSIT draft Guidance [INQ00047871 §§17-18] White [INQ000474743/91/91 §§8.5-8.6] Hughes [T9/20/10-4]. See also Butler [INQ000474479/11 §§7.1-7.3, 39.1] Gabbay [INQ000474396/22 §61]

payment on results,[157] or cost benefit analysis could be more adventurous because of the grave price of doing nothing. For medical conditions that are underrepresented, pathways into clinical trials and research will sometimes only be forged through patient lobbying, designed participation, and access afforded to representative groups to champion change.[158] The public, and particularly the representatives of groups that are both medically and socially vulnerable to the lack of diversity in the system of pharmaceutical development, need to become research participants and dialogue partners.[159] For that, those groups need both to be properly welcomed in and to organise dynamically to join up.

## [E]. DAMAGE

43. DISABLED PEOPLE: The experience of the vaccine damaged and bereaved is an example of how society disables people. Familiar stages of disablement that are relevant here, include: (1) inaccessible processes and communications (including that the Yellow Card means to report suspected vaccine side effects or adverse events is not AIS compatible),[160] (2) a clinical response to disability focussed on individual medical and personal circumstances, (3) resistance to diagnosis and a heavy burden of 'proving' causation, (4) characterising the condition as anomaly/abnormality/tragedy, (5) subjecting Disabled people seeking financial assistance to demeaning and debilitating bureaucracy and delay,[161] (6) blaming, stigmatising, and suppressing the victim,[162] (7) pricing responsibility to a Disabled person within arbitrary figures (£120,000) based upon eligibility levels of severe bodily impairment (60% disability) and inappropriate analogy (the DWP test for industrial injuries).[163] Jamie Scott's story, as told by Kate Scott, exemplifies aspects of what Disabled people go through routinely.[164]

44. AFTERTHOUGHT: The VDPS is a paradigm of afterthought and exclusion. Little has changed since the scheme was introduced in 1979 after the Pearson Commission,[165] which had recommended "*compensation*" not damage payment, with little incentive since then to revisit its fitness for purpose to encourage vaccination as an act of personal and collective health.[166] VDPS was largely administered by the DWP until 2021, when it was transferred to DHSC given the increase of applications due to Covid-19 vaccines, but with no prior planning and inevitable delays caused

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[157] Javid-Barclay WhatsApp 13.08.22 10:52:20 [INQ000327491/7]
[158] Bingham [T6/73/3-74/9]
[159] White [INQ000474743/91/87 §7.7.6] [T12/37/22-38/20]
[160] *First Do No Harm* [INQ000486333/21 §1.43] O'Rafferty [INQ000497102/59 §181]
[161] Moore [INQ000474459/14 §§56-58]
[162] Moore [INQ000474459/15 §§59-61]
[163] Moore [INQ000474459/8 §§27-31, 83-84] Moore [T11/16/9-17/25] Caulfield 19.06.23 [INQ000414140] Swinson [INQ000474333/92 §258(a)]
[164] Scott [T2/151/16-154/23] [T2/155/8-160/20]
[165] Pearson Commission [INQ000411782/316 §§1408-09, p. 389 Rec. 158] Swinson [INQ000474333/87 §239]
[166] Moore [T11/2/9-4/10] [INQ000474459/ §§16-18] Fairgreave [INQ000474539/5 §§12, 22-24] Fairgreave et al [INQ000414146/16-17]

by the transfer.[167] Aside from a brief government review in May 2022, nothing has been done seriously to reconsider eligibility thresholds, graduated payments or enhanced awards.[168] Several ex-Ministers have suggested that should happen.[169] The anomaly is not sensible for maintaining the reputation of vaccines, but it also strikes at the values of collective responsibility that pandemic vaccination depended upon. Just as the outcome in relation to vaccine alternatives indicates a failing of social solidarity with a substantial part of the population, the same is true of the current outdated thresholds, awards and operation of the VDPS.

## [IV]. SOLUTIONS

45. VULNERABILITY: All the barriers identified above were foreseeable. They could have been addressed with proper planning and co-production involving Disabled people and DPO. Other civil society groups could make the same claim. The fact that barriers remained, even for Disabled people who are such a sizeable part of the population, reveals a profound lack of collective resilience. It is the system that is vulnerable not people. That is the case, despite material wealth and technical capability to create vaccines in the first place. The prospects[170] of state and society being more responsive to one another in a time of crisis requires METHOD, ORGANISATION and fuller appreciation of our INTERDEPENDENCE.

46. METHOD: It is essential to both trust and equitable outcomes for government to see people and representative organisations as a resource, and to look for solutions from bottom up not just top down. Systemic partnership and accountability to community groups, including Disabled groups, during vaccine delivery was not a heightened unnecessary degree of administrative process that would slow the system down. It was rather the crucial means to ensure tailored delivery processes at the outset and achieve course-correction when needed.[171] To that end DPO commend human rights and structured social and ethical analysis as practical and methodological tools to build resilient systems. Targeted community engagement is as important as engagement with business, labour, and expertise.[172]

47. ORGANISATION: Matters of structural inequality and hard case ethical conundrums cannot be resolved by relying on good faith, exceptional leadership or certain types of expertise.[173] The qualities of participatory policy building include[174] (1) CO-PRODUCTION at the design stage, and

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[167] Moore [T11/11/7-20]. See also Swinson [INQ000474333/89 §§243-245]

[168] Swinson [INQ000474333/91 §270] Fairgreave [INQ000474539/7 §§18, 43-51]

[169] Sharma [T4/31/19-32/5] Javid [T8/55/10-56/15] Richardson [T10/100/21-101/22]

[170] For DPO Module 2 submissions on resilience enhancement, see DPO M2B Closing 05.04.24 [§§20-40]

[171] Kasstan-Dabush [T10/176/14-177/24] [T11/189/23-190/6] [T10/198/17-199/4] [INQ000474623 §§359,380b.]

[172] Enria et al [M2/INQ000273365/1-2] Sedwill [M2/INQ000182382/6] [M2/T20/151/16-153/20] O'Donnell [M2/INQ000189722/20-21] Bear et al [M2/INQ000273376]

[173] Whitty [T5/67/15-69/3] Van-Tam [T5/146/3-148/11] Badenoch [T9/37/24-38/7] Bingham [T6/69/6-17]. *Cf.* DPO M2B Closing 05.04.24 [§22]

[174] Reicher [M2/INQ000273800/16 §47] Burgess et al [M2/INQ000273405]

ongoing meaningful engagement in relation to equality impact assessment[175] and data.[176] (2) INTEGRATION of representative organisations, and their local networks, into a two-way pipeline of ideas, information, and action. (3) DIALOGUE – most imperatively about difficult matters. (4) FACILITATION of representative groups such as DPO to be management consultants and co-leaders, not just volunteers.[177]

48. INTERDEPENDENCE: Vaccines came at a point in time when the social disparities of the pandemic in terms of death and suffering had become obvious. Under existential threat of whole-society emergency there was an unusual window of political will to engage with these inequalities. To do so more successfully in future pandemics, policymaking should be infused with an ethics of care that recognises both our interdependence – as well as the precarity of marginalised populations. Disabled people's complex access to Covid pharmaceutical solutions shows that we are not there yet, but we could be.

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**17 FEBRUARY 2025**

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[175] DPO M2B Closing 05.04.24 [§32] Foster [M2B/T2/100/18-101/9] Holland [M2B/T2/183/10-184/8] [M2B/T2/186/2-4] Swinson [T4/137/19-138/6]

[176] DPO M2B Closing 05.04.24 [§35] Freeguard [M2/INQ000260629/48 §§95, 97,113-114] John [M2B/INQ000286066/37 §§6.75-6.79] [M2B/T4/129/14-132/3] Sudlow [INQ000513700/17, 20 Rec.3]

[177] Watson & Shakespeare [INQ000280067/12 §38] Fernandes-Jesus et al [M2/INQ000273352] Cullingworth et al "*They have been a saving grace in all this*"*: the role of the third sector in disabled people's experiences of COVID-19 and implications for sector–state relations* Voluntary Sector Review 2022: 1–18, pp 1-2, 15