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## Response

### Mission Creep in Newborn Screening and DNA Forensics

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During the Somali Civil War, several major newspapers cited concerns about “mission creep” with respect to the military’s involvement in Operation Restore Hope. The project was a humanitarian effort to protect relief agencies’ food-distribution operations and feed starving children in Somalia.<sup>1</sup> One journalist warned that “[m]ission creep—the temptation commanders feel to chase success and perhaps glory around the next corner by expanding their mandate and rolling over anyone in their way—threatens to take hold in Mogadishu.”<sup>2</sup> And indeed, the mission soon morphed into broader efforts to disarm Somali warlords and free allied bases surrounded by Somali militia forces.<sup>3</sup> As Marine Maj. Gen. Tony Zinni, a member of Operation Restore Hope, described it: “We thought after the first 30 days we’d done our job (in Somalia). Then, after 60 days, we found ourselves in ‘mission creep.’”<sup>4</sup>

The term “mission creep” likely first appeared in 1993 with respect to military humanitarian missions in Somalia and elsewhere.<sup>5</sup> Ten years later,

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1. David Evans, *‘Mission Creep’ Alarms U.S.*, CHI. TRIB. (June 22, 1993), <https://www.chicagotribune.com/news/ct-xpm-1993-06-22-9306220211-story.html> [<https://perma.cc/48K3-58UG>]; Jim Hoagland, *Beware ‘Mission Creep’ in Somalia*, WASH. POST (July 20, 1993), <https://www.washingtonpost.com/archive/opinions/1993/07/20/beware-mission-creep-in-somalia/fe98b9e2-9ceb-45c3-babf-844a8a2671e9/> [<https://perma.cc/C8BY-PNAE>].

2. Hoagland, *supra* note 1.

3. Evans, *supra* note 1 at 3; John H. Cushman, Jr., *Mission in Somalia Is to Secure City*, N.Y. TIMES (Oct. 10, 1993), <https://www.nytimes.com/1993/10/10/world/mission-in-somalia-is-to-secure-city.html> [<https://perma.cc/L4B6-C4YJ>].

4. Evans, *supra* note 1.

5. Charles E. White, *Mission Creep During the Lewis and Clark Expedition*, U.S. ARMY CTR. OF MIL. HIST.: LEWIS & CLARK CORPS OF DISCOVERY (Jan. 31, 2021), <https://history.army.mil/lc>

an Army Field Manual described it as a unit receiving “shifting guidance or [a] change in mission for which the unit is not properly configured or resourced” or attempting “to do more than is allowed in the current mandate and mission.”<sup>6</sup> That second description matches the dictionary definition: a “gradual broadening of the original objectives of a mission or organization.”<sup>7</sup> Natalie Ram’s article, *America’s Hidden National DNA Database*<sup>8</sup> never mentions the term “mission creep.” But she depicts precisely that. Indeed, her article is a cautionary tale about the phenomenon arising in two unrelated areas—newborn screening and DNA forensics—such that two very different governmental activities—public health and law enforcement—intersect. Having written about the risks of mission creep in both areas<sup>9</sup> and warned of the potential intersection of the two,<sup>10</sup> I find her project particularly compelling and am deeply sympathetic to her concerns.

My response begins in Part I by showing how Ram’s account of the evolution of newborn screening and DNA forensics illustrates two versions of mission creep, which are now at risk of overlapping. Part II discusses how her research and other considerations help explain what makes mission creep possible in this context. Finally, Part III, the main focus of this response, expands upon Ram’s concerns about this mission creep. She articulates three reasons to prevent law enforcement use of newborn screening resources: to preserve public trust, to affirm respect for persons, and to observe constitutional boundaries.<sup>11</sup> Focusing on the first two, my response argues that these concerns are even greater if one understands some of the deficiencies of newborn screening programs. Finally, my response ends by addressing and rejecting an argument in favor of mission creep—that it promotes justice. Instead, I argue that mission creep would only enhance racial injustices because the harms of mission creep would disproportionately affect minorities.

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/the%20mission/mission\_creep.htm [https://perma.cc/M96B-R7KW]; see also Evans, *supra* note 1 (describing mission creep in the Kurdish relief operation after the 1991 Persian Gulf War).

6. U.S. DEP’T OF THE ARMY, FIELD MANUAL 3-07 (FM 100-20), STABILITY OPERATIONS AND SUPPORT OPERATIONS 1-17 (2003).

7. *Mission Creep*, MERRIAM-WEBSTER.COM, <https://www.merriam-webster.com/dictionary/mission%20creep> [https://perma.cc/K42H-B9ZC].

8. Natalie Ram, *America’s Hidden National DNA Database*, 100 TEXAS L. REV. 1253 (2022).

9. Sonia M. Suter, *Did You Give the Government Your Baby’s DNA? Rethinking Consent in Newborn Screening*, 15 MINN. J.L. SCI. & TECH. 729, 745 (2014) [hereinafter Suter, *Rethinking*] (describing that problem implicitly); Sonia M. Suter, *All in the Family: Privacy and DNA Familial Searching*, 23 HARV. J.L. & TECH. 309, 317–18 (2010) [hereinafter Suter, *AITF*] (describing mission creep explicitly).

10. Suter, *Rethinking*, *supra* note 9, at 755.

11. Ram, *supra* note 8, at 1301.

## I. Mission Creep

Ram briefly lays out the evolution of newborn screening and DNA forensics, demonstrating how the approach and even ultimate goals of each endeavor have expanded—what I call “mission creep.” For example, she describes how newborn screening, which arose as a public health program to screen for a single preventable and heritable disease, phenylketonuria (PKU), “slowly and haphazardly” expanded to include a much broader range of conditions.<sup>12</sup> Part of this expansion is due to technological advances that enable broader screening, which she notes may ultimately lead to whole-genome or whole-exome sequencing.<sup>13</sup> As she concludes, “[N]ewborn screening programs have evolved substantially over time . . . in ways that take them far afield from their initial intended purpose.”<sup>14</sup>

The mission creep in newborn screening also includes the retention of NBS samples and information. The original justifications for sample and data retention were linked to the goals of newborn screening (allowing for follow-up tests, quality assurance, or establishing the prevalence of the screened-for conditions).<sup>15</sup> As the breadth of screening has grown, so too have the secondary uses of the stored information and samples, including paternity testing, research unrelated to newborn screening, and now law enforcement.<sup>16</sup> As Ram points out, it is “far from clear” that the original justifications for newborn screening “support the subsequent retention and use of those samples for other purposes.”<sup>17</sup>

Mission creep has also shaped the evolution of DNA forensics in law enforcement. First, it has dramatically expanded the categories of people whose DNA is stored in the centralized government database—from sex offenders, to felons, to misdemeanants, and finally to arrestees.<sup>18</sup> In addition, the databases law enforcement uses for forensic investigations have expanded beyond the Combined DNA Index System (CODIS) database—a centralized and well-regulated government database created precisely for forensics<sup>19</sup>—to include consumer-genetic platforms, which were created for personal use.<sup>20</sup>

Ram recognizes that the worries about law enforcement using newborn screening databases (or as I describe it, the merging of two types of mission

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12. *Id.* at 1259–60.

13. *Id.* at 1260, 1265–67, 1266 n.81; *see also* Suter, *AITF*, *supra* note 9, at 317 (discussing the same expansion).

14. Ram, *supra* note 8, at 1268.

15. Suter, *Rethinking*, *supra* note 9, at 755.

16. *Id.* at 755–56.

17. Ram, *supra* note 8, at 1262.

18. *Id.* at 1269.

19. *Id.* at 1268.

20. *Id.* at 1270.

creep) are not new. Indeed, I raised the concern eight years ago that mission creep in newborn screening could allow law enforcement access to newborn screening samples.<sup>21</sup> While the risk was more theoretical then, Ram makes clear how much more imminent it is today. Genetic surveillance through DNA forensics was originally limited to individuals with reduced expectations of privacy because of criminal convictions. But with the Supreme Court sanctioning the inclusion of DNA profiles from arrestees in government databases<sup>22</sup> and the current prevalence of consumer genetic databases that hold DNA profiles created for reasons completely unrelated to law enforcement, some of the barriers against using newborn screening for law enforcement have diminished.<sup>23</sup> These changes have eroded the notion that only convicted individuals should be surveilled, making it easier for law enforcement to consider probing DNA databases that were not created for forensic purposes. Second, investigative genetic genealogy, which uses genetic profiles from consumer databases that can reveal sensitive information about diseases and traits, challenges the original view that only noncoding segments utilized for the CODIS database can be used for forensics.<sup>24</sup> Together these changes bring us one step closer to DNA forensics in newborn screening databases.

## II. What Makes Mission Creep Possible

Mission creep, of course, is not unique to humanitarian military missions, newborn screening, or DNA forensics. While Ram does not speak in terms of mission creep, her article indirectly highlights one underlying cause for this phenomenon: a lack of imagination. Her empirical research reveals the ways in which legislatures and policymakers fail to contemplate or protect against the possibility that a project's original parameters can morph and expand if guardrails are not in place. As her data show, "most states have not grappled sufficiently—or at all—with the question of law enforcement access to newborn screening resources," even when states have "some discernible policy in place."<sup>25</sup> Indeed, about 27% of jurisdictions have inconclusive or no articulated policies governing law enforcement access to newborn screening databases and related data.<sup>26</sup> And where states have policies permitting access to newborn screening databases, they generally do not exist in laws geared specifically toward newborn screening. Instead, they

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21. Suter, *Rethinking*, *supra* note 9, at 755.

22. *Maryland v. King*, 569 U.S. 435, 465–66 (2013).

23. *See* Ram, *supra* note 8, at 1270 (discussing the use of consumer genetic databases to locate the Golden State Killer).

24. *Id.* at 1274.

25. *Id.* at 1280.

26. *Id.* at 1277, 1278 fig.2 (indicating that fourteen out of fifty-one jurisdictions—comprising 50 states and the District of Columbia—have no articulated policy).

emerge from general privacy statutes, which have exceptions for law enforcement,<sup>27</sup> presumably developed with the view that forensic uses of DNA would involve only government-created forensic databases. In other words, mission creep is possible because policymakers didn't envision it as a risk.

Some of this failure of imagination can be attributed to changes in technology that may not have been foreseeable when newborn screening and even DNA forensics first emerged. Legislatures may not have contemplated the use of whole-genome sequencing for newborn screening when genetics was less advanced and newborn screening only assessed metabolites as indirect measures of heritable genetic conditions. Nor did they envision the use of genomics to create recreational databases for genealogy studies, let alone their value to law enforcement. On the other hand, even if the precise technologies were not fully imaginable, legislators should have foreseen the possibility that technological advancements of some sort would increase the ability to glean information from biological samples and related data. Ram's piece, in other words, is an indirect call for legislatures to be less myopic about the positive benefits of technology and to remain vigilant about the risks of what is almost always a double-edged sword.

Ram does not address, at least directly, an additional reason for mission creep: the fact that the original mission is often driven by concrete, tangible, and undeniably valuable goals—e.g., saving newborns from preventable and life-threatening or serious diseases, preventing further murders or rapes by solving cold cases, identifying serial perpetrators and exonerating the wrongfully convicted—whereas the risks of the mission are often more amorphous and difficult to measure—e.g., threats to privacy and liberty.<sup>28</sup> When cost-benefit analysis is used for policymaking (as it often is), the more nebulous risks are often hard to measure and weigh against the concrete, visceral benefits. Thus, it is easy to push the scope of a mission here and there to, for example, save more lives or prevent more crimes, while failing to recognize the increasing costs, such as threatening privacy and liberty, and the potential deviation from and inadvertent undermining of the mission's original goals. As a result, the goalposts can move, a little bit at a time, until gradually but surely the means to achieve the end goal become quite different from what was initially envisioned.

The combination of a lack of legislative imagination—as exposed by Ram's research—and the difficult weighting of amorphous values like privacy and liberty create the particular risk of mission creep that Ram describes: the use of newborn screening resources for law enforcement investigations. The next section underscores and expands upon Ram's

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27. *Id.* at 1286–87.

28. See Suter, *Rethinking*, *supra* note 9, at 762; Suter, *AITF*, *supra* note 9, at 375.

articulation of reasons to be troubled by state policies that do not preclude, and may even allow, law enforcement's use of newborn screening resources.

### III. The Risks of Mission Creep

Ram's piece ends by emphasizing what are essentially the amorphous costs of mission creep when law enforcement intersects with newborn screening: undermining public trust, undermining respect for persons, and challenging constitutional values. Sympathetic to her concerns, my response focuses on and expands upon the first two concerns by pointing to deficiencies in newborn screening programs that intensify them: inadequate consent and prior forms of mission creep in newborn screening that have already undercut its primary mission to some extent. It ends with a brief discussion as to why arguments rooted in concerns for justice do not justify these risks and may actually perpetuate injustices.

#### A. *Public Trust*

I begin with concerns about maintaining public trust. Newborn screening programs have long demonstrated indifference to parental consent generally, and especially to *informed* consent, not only regarding the storage and secondary uses of the samples but also the initial process of collecting and screening samples. Ram observes that “[t]hroughout the history of state newborn screening programs, states have given little role to parental consent,” rarely seeking “[a]ffirmative parental consent” for the screening.<sup>29</sup> She notes further that “states have often eschewed *informed* consent,” asserting “their general public health powers or *parens patriae* authority [to] authorize nonconsensual newborn screening, or at least permit consent to be presumed.”<sup>30</sup> And finally, she describes newborn screening as “largely ‘automatic,’” treated as “standard newborn care to which new parents are not asked affirmatively to consent and to which they must instead affirmatively object.”<sup>31</sup>

These statements, however, do not capture the degree to which parents of newborns are often *uninformed* about newborn screening itself—not just the types of conditions screened for or the fact that many states may store and use them for other purposes but also the basic fact that samples will be, or have been, collected for analysis. As I have observed, parents are “often woefully uninformed about” newborn screening.<sup>32</sup> Healthcare providers often have limited knowledge about their states’ screening policies or even

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29. Ram, *supra* note 8, at 1261.

30. *Id.* at 1308–09 (emphasis added).

31. *Id.* at 1322.

32. Suter, *Rethinking*, *supra* note 9, at 747.

the need to initiate discussion with patients about the process.<sup>33</sup> As a result, parents may receive very limited information about the nature of newborn screening or even that it is occurring, let alone their right to opt out (in states that allow that).<sup>34</sup> The dearth of information, unfortunately, sometimes even exists in cases where a child has tested positive, when some parents do not receive genetic counseling or any education about the condition.<sup>35</sup>

This fact alone minimizes the effectiveness of screening programs. As I have argued, requiring parents to opt into newborn screening after being educated generally about newborn screening—a process that can be achieved in five minutes or less<sup>36</sup>—would lead to more screening, not less. Studies show that refusal rates are low when parents are informed of newborn screening. Moreover, if parents are aware of screening, they could provide an additional check to ensure that screening is actually done and results are shared.<sup>37</sup>

The deficiencies regarding consent pose significant problems for public trust. If parents are kept out of the loop, only to discover later that samples from their children have been taken, retained, and then used for purposes that do not protect the children's well-being, the sense of betrayal and distrust would be especially great. Ram focuses a great deal on the harm of distrust in public health efforts like vaccination and contact tracing where, as we have seen with COVID-19, distrust has led to far lower rates of adoption than optimal.<sup>38</sup> And she rightly notes that, given the “deeply sensitive and highly revealing” information in newborn screening samples and related data, newborn screening programs might be “similarly imperiled if the public comes to see this existing public health program through a law enforcement lens.”<sup>39</sup>

The comparisons are not completely apt, however, because newborn screening is involuntary, unlike digital contact tracing (or vaccination) for COVID-19. Indeed, the *lack* of voluntariness of newborn screening is justified by the public health goals of the programs.<sup>40</sup> I would argue, therefore, that the threat to public trust is even greater for newborn screening

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33. Rachel L. Schweers, *Newborn Screening Programs: How Do We Best Protect Privacy Rights While Ensuring Optimal Newborn Health?*, 61 DEPAUL L. REV. 869, 869 (2012).

34. Suter, *Rethinking*, *supra* note 9, at 747.

35. *Id.*

36. Ruth Faden, A. Judith Chwalow, Neil A. Holtzman & Susan D. Horn, *A Survey to Evaluate Parental Consent as Public Policy for Neonatal Screening*, 72 AM. J. PUB. HEALTH 1347, 1350 (1982).

37. Suter, *Rethinking*, *supra* note 9, at 783–84.

38. Ram, *supra* note 8, at 1305.

39. *Id.*

40. Ram, *supra* note 8, at 1254–55 (“[N]early all infants born in America are compelled to give their DNA to the government” for newborn screening programs, which are “a critical part of our public health infrastructure.”).

precisely *because* of the lack of consent. If law enforcement began to surveil newborn screening samples, there would of course be concerns about the use of samples obtained “as part of ordinary care,”<sup>41</sup> but the outrage would be multiplied by the fact that the government had initially departed from medical norms by performing medical testing on infants without affirmative consent from the parents.<sup>42</sup> The idea that the state justifies limiting parental autonomy based on the doctrine of *parens patriae* would add insult to injury. If the state usurps control over intimate personal biological samples and associated medical information by stepping in as “parents of the country” and then uses those involuntarily collected samples for its own surveillance, that is worse than “overweening government power.”<sup>43</sup> It is akin to abuse of power.

Ram uses the *Ferguson v. City of Charleston*<sup>44</sup> case as an illustration of these concerns.<sup>45</sup> That case ruled that there was a Fourth Amendment violation in coercing pregnant women who tested positive for drugs to join drug treatment programs by threatening to make those results available to law enforcement.<sup>46</sup> Ram doesn’t spell out the fact that the Supreme Court reached its conclusion under the assumption that “the tests were performed *without* the informed consent of the patients.”<sup>47</sup> While they may have consented to the collection of urine samples by their physician, there was reason to doubt that they consented either to the drug analysis or the release of the information to the police.<sup>48</sup> Thus, the government overreached not only in violating the reasonable expectation of privacy of patients by sharing the results of diagnostic tests with nonmedical personnel without the patient’s consent<sup>49</sup> but also in collecting the information about drug use in the first place without informed or possibly any consent, especially when the samples

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41. *Id.* at 1307.

42. Suter, *Rethinking*, *supra* note 9, at 746.

43. Ram, *supra* note 8, at 1303.

44. 532 U.S. 67 (2001).

45. Ram, *supra* note 8, at 1305.

46. *Ferguson*, 532 U.S. at 70, 85–86.

47. *Id.* at 77 (emphasis added).

48. *Id.* at 93 (Scalia, J., dissenting). In his *Ferguson* dissent, Scalia described the levels of consent at play:

The only conceivable bases for saying that [the urine samples] were obtained without consent are the contentions (1) that the consent was coerced by the patients’ need for medical treatment, (2) that the consent was uninformed because the patients were not told that the tests would include testing for drugs, and (3) that the consent was uninformed because the patients were not told that the results of the tests would be provided to the police. (When the court below said that it was reserving the factual issue of consent, . . . it was referring at most to these three—and perhaps just to the last two.)

*Id.* (Scalia, J., dissenting).

49. *Id.* at 78.



could be used for dual purposes of medical care and law enforcement.<sup>50</sup> The concerns motivating the decision in *Ferguson* were both the *unconsented* collection of information from biological material and the use of that material and related test results for law enforcement purposes.

Additional deficiencies in newborn screening only add to the possibility for public mistrust. As I have noted, some of the mission creep in newborn screening cannot be justified under the *parens patriae* doctrine and the goal of preventing early childhood diseases or death. First, states often do not provide treatment for affected children; instead, some merely identify those at risk, leaving families to seek out treatment, which somewhat undermines the primary goal of screening.<sup>51</sup> Second, newborn screening now includes a broad range of conditions, including those for which there is no treatment or that are not fully understood.<sup>52</sup> The rationale for including those conditions cannot be that they prevent early childhood diseases. Instead, the justifications for newborn screening have expanded to include the value of learning about the natural history of some diseases and providing parents with information to enable reproductive choices.<sup>53</sup>

At the same time, the broadening goals of newborn screening have made the use of whole-genome or whole-exome testing in this context even more likely.<sup>54</sup> If such testing becomes part of newborn screening, it would create a richer and more comprehensive database of information, which could be used for both medical and nonmedical purposes. That expansion of information comes with costs, however, even when limited to medical purposes. It increases the possibility of false positives, false negatives, and variants of uncertain significance, potentially leading to stress and anxiety and costly diagnostic odysseys.<sup>55</sup> Those features, as I have argued, are problematic given how much newborn screening practices depart from medical norms by not requiring affirmative, informed consent,<sup>56</sup> especially when the justifications for screening expansions include interests other than the newborn's best interests.<sup>57</sup>

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50. The dissent challenged the assumption that consent had not been granted to collect the urine samples and therefore concluded that no search had taken place and that there was no Fourth Amendment violation. *Id.* at 93 (Scalia, J., dissenting).

51. Suter, *Rethinking*, *supra* note 9, at 752.

52. *Id.* at 742.

53. *Id.* at 738–39, 745.

54. Ram, *supra* note 8, at 1266 (discussing proposals that “have sought to introduce genome-wide sequencing to newborn screening.”).

55. Suter, *AITF*, *supra* note 9, at 319 n.63 (“[I]nvestigators would have to check out false positives . . . consuming time and invading the privacy of innocent people.”).

56. “Mandatory genetic testing is extremely unusual, in large part because a strong consensus has existed for some time that genetic screening programs should not be compulsory and should involve informed consent.” Suter, *Rethinking*, *supra* note 9, at 748 (footnote omitted); *see also* Faden, *supra* note 36, at 1347–48.

57. *See supra* text accompanying note 53.

This richer pool of data, as Ram points out, also makes newborn screening data even more desirable for law enforcement purposes. Thus, the concerns about undermining public trust exist on several fronts. As the justifications for obtaining samples without affirmative (let alone informed) consent weaken, and as the uses expand to make law enforcement surveillance easier and more desirable, public trust will evaporate. Ram cites the concern that “some parents [may] decline or evade screening entirely.”<sup>58</sup> That is certainly a risk, at least in jurisdictions where they *can* opt out. But given the broad expansion of newborn screening itself, one might also worry that parents will mobilize to undermine the endeavor altogether, not just the retention and secondary use of samples. People may soon see the collection of samples as rooted in the government’s surveillance interests. In their eyes, the government would act less like a steward of their newborn’s personal information and more like a fox in the henhouse. At best, the public would clamor for the protections Ram wants implemented. But at worst, there would be efforts to completely undercut the project. In an era where conspiracy theories and disinformation regarding public health measures have blossomed, there is real reason to worry. If as many as 20% of Americans believe it is “definitely true” or “probably true” that the “U.S. government is using the COVID-19 vaccine to microchip the population,” and as many as 14% are unsure,<sup>59</sup> one could envision sizeable factions conflating newborn screening with government surveillance. Most people do not know anything about newborn screening. If their first awareness of it comes from publicity about law enforcement uses of the samples, such conflation would be even more likely. Moreover, unlike conspiracy theories about microchips in vaccines, which are not at all rooted in reality, law enforcement surveillance of newborn screening would be a fact, even if not the *raison d’être* of newborn screening. It is easy, therefore, to imagine that the outcries and opposition would be similar to, if not dwarf, those surrounding COVID-19 vaccines and digital contact tracing.

### B. *Affirming Respect*

Ram’s second rationale for keeping law enforcement out of newborn screening samples is to affirm respect for persons by treating those with capacity as autonomous agents and protecting those with diminished

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58. Ram, *supra* note 8, at 1307.

59. THE ECONOMIST/YOUGOV POLL: JULY 10–13, 2021—1500 U.S. ADULT CITIZENS 132 (2021), <https://docs.cdn.yougov.com/w2zmpzsq0/econTabReport.pdf> [<https://perma.cc/RXT7-42EB>]; see also Jenna Romaine, *Alarming Number of Americans Think Vaccines Contain Microchips to Control People*, HILL (July 19, 2021), <https://thehill.com/changing-america/well-being/prevention-cures/563669-alarming-number-of-americans-think-vaccines/> [<https://perma.cc/HG6X-DZWG>].

autonomy.<sup>60</sup> She notes that although informed consent is typically used to demonstrate such respect in healthcare, exceptions apply to areas like newborn screening and research of deidentified biospecimens. She questions whether this approach makes sense for research of newborn screening samples, noting that courts have “acknowledged that respect for persons may be inconsistent with the nonconsensual research use of newborn screening resources, even if consent is not required for the public health newborn screening itself.”<sup>61</sup>

Unlike Ram, I have critiqued the lack of consent for the screening itself, particularly given the scope of mission creep in newborn screening.<sup>62</sup> But like her, I have also criticized the use of newborn screening biobanks for research. While I recognize they may offer valuable research treasure troves, I see them as “unique in implicating particularly salient privacy and autonomy interests.”<sup>63</sup> As noted above, most parents have not consented to, or have not even been made aware of the possibility of, the collection and analysis of their newborns’ blood spots. That is not the case with respect to other biobanks, where the source of the biospecimens consented to the initial collection and analysis of their tissue (whether or not they did so for secondary research). And, of course, in most states, parents have not consented to and often are not even aware of the retention and use of the samples for other purposes.

Another concern, which Ram does not emphasize, is that these samples are obtained from minors, a group deemed vulnerable under the Common Rule and deserving of heightened protection.<sup>64</sup> The state should make extra efforts to safeguard their privacy and liberty given their incapacity to consent. Unlike consumers who choose to put their genetic information in consumer genetic platforms, the minor has not decided to have their genetic information stored and accessible by researchers or the government for any purpose, especially those unrelated to their well-being. If newborn screening is grounded on the *parens patriae* doctrine, the government should be a steward of the biospecimens and related data with the “fiduciary obligation to protect the autonomy and privacy interests of the newborn.”<sup>65</sup> Although I previously conceded the impracticability of seeking detailed informed consent for research uses; the value of research on these samples; and the small, though not inconsequential, risk of consent bias in requiring parents to opt in to retain newborns’ samples and use them for research, I nevertheless advocated for a

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60. Ram, *supra* note 8, at 1308.

61. *Id.* at 1310.

62. Suter, *Rethinking*, *supra* note 9, at 779–89.

63. *Id.* at 769.

64. *Id.* at 769–70.

65. *Id.* at 770.

general-consent requirement for retention and secondary uses, even for deidentified research. In part, the motivation was, as discussed above, to strengthen public trust in newborn screening programs.<sup>66</sup> In addition, I argued that such an approach was necessary to appropriately value the amorphous privacy and autonomy interests, which are far too undervalued in the current system.<sup>67</sup>

Those same arguments apply even more strongly with respect to secondary *law enforcement* use of the samples. First, unlike research on the samples, which can in theory be deidentified, using these samples for forensic purposes necessarily requires them to be identifiable. As Ram points out, there is “no small risk” in subjecting individuals to their loss of liberty through such use of their samples.<sup>68</sup> If the government asserts its role as caretaker of the child under the *parens patriae* doctrine to collect the minor’s samples without affirmative parental consent, then a minimal requirement should be that it takes great care to protect against undesirable and potentially harmful uses of those samples and related information. Parents are generally given broad discretion in decision making with respect to their children under the theory that the “natural bonds of affection lead parents to act in the best interests of their children.”<sup>69</sup> If the government steps into the parental role on behalf of the minor, the expectation should be that it will act in the minor’s best interest.<sup>70</sup> Allowing for mission creep that subjects minors to a lifetime of government surveillance would certainly not promote their best interests. Quite the contrary: it would undermine them.

### C. Justice Concerns

I end with an issue Ram does not address: the justice arguments supporting law enforcement’s use of newborn screening resources for DNA forensics. A serious critique of the CODIS database is that, due to disproportionate rates of arrest, prosecution, and conviction, minorities are overrepresented in the national database.<sup>71</sup> Some have argued that universal databases, including newborn screening databases, could remedy these

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66. *Id.* at 777.

67. *Id.* at 779.

68. Ram, *supra* note 8, at 1310.

69. *Parham v. J.R.*, 442 U.S. 584, 602 (1979).

70. See generally Elizabeth S. Scott & Robert E. Scott, *Parents as Fiduciaries*, 81 VA. L. REV. 2401 (1995) (outlining a model for treating parents as fiduciaries and applying those principles to contemporary family law). This justification for parental rights has, however, been criticized as an ideal that is not always realized and that can result in harm to children. See generally Samantha Goodwin, *Against Parental Rights*, 47 COL. HUM. RIGHTS L. REV. 1 (2015).

71. Twelve percent of the US population is African American, but 40% of the genetic profiles in the CODIS database are from that population. Solomon Moore, *F.B.I. and States Vastly Expanding Databases of DNA*, N.Y. TIMES (Apr. 19, 2009), <https://www.nytimes.com/2009/04/19/us/19DNA.html> [<https://perma.cc/DP65-2655>].

disparities.<sup>72</sup> Others have further argued that universal databases would enhance privacy by reducing the need for more intrusive investigative techniques, particularly if the government destroyed the samples and restricted their use.<sup>73</sup>

The justice argument is the most persuasive reason to allow the mission creep that Ram warns against. Ultimately, however, it would threaten the privacy and liberty of everyone and promote further mission creep without addressing the societal factors that underlie racial disparities. In theory, the government could limit the uses of these samples, but as new technologies provide broader investigative benefits, there is reason to fear further, unabated mission creep in this area. Moreover, with societal racism spilling into the criminal justice system,<sup>74</sup> heightened surveillance—even against everyone—will likely be disproportionately used against minorities. Imagine the government using these databases to develop DNA phenotyping for use in racial profiling in the United States as some fear the Chinese may do against the Uighurs.<sup>75</sup> In other words, using newborn screening samples for DNA forensics would only provide a band-aid to serious criminal injustice, while further undermining public trust and respect for everyone, especially minorities.

In short, Ram is right to call for legislative attention to these problems of mission creep and to develop policies that address the issues head on. Otherwise, there seems no limit to the scope of mission creep.

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72. D. H. Kaye & Michael E. Smith, *DNA Databases for Law Enforcement: The Coverage Question and the Case for a Population-Wide Database*, in *DNA AND THE CRIMINAL JUSTICE SYSTEM: THE TECHNOLOGY OF JUSTICE* 247, 269–71 (David Lazer ed., 2004).

73. Kirsten Dedrickson, *Universal DNA Databases: A Way to Improve Privacy?*, 4 *J.L. & BIOSCI.* 637, 645–47 (2018).

74. SENT’G PROJECT, *REDUCING RACIAL DISPARITY IN THE CRIMINAL JUSTICE SYSTEM: A MANUAL FOR PRACTITIONERS AND POLICYMAKERS* 9 (2000), <https://www.sentencingproject.org/wp-content/uploads/2016/01/Reducing-Racial-Disparity-in-the-Criminal-Justice-System-A-Manual-for-Practitioners-and-Policymakers.pdf> [<https://perma.cc/3A3D-U2LV>] (“So long as racism exists within society at large, it will be found within the criminal justice system.”).

75. Sui-Lee Wee & Paul Mozur, *China Uses DNA to Map Faces, with Help from the West*, *N.Y. TIMES* (Dec. 3, 2019), <https://www.nytimes.com/2019/12/03/business/china-dna-uighurs-xinjiang.html> [<https://perma.cc/5EEE-WE33>].