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Guarding the child's health: Legal and ethical tensions in newborn screening in Türkiye

Ezgi Sancaroğlu Yavuzer[1], Gürkan Sert[2], Maide Barış[3]

[1] Health Law Doctorate Programme, Institute of Social Sciences, Istanbul Medipol University. Istanbul / Türkiye
https://orcid.org/0000-0003-0059-6919

[2] Department of Medical History and Ethics, Faculty of Medicine, Marmara University. Istanbul / Türkiye
https://orcid.org/0000-0002-0970-8406

[3] Department of Medical History and Ethics, Faculty of Medicine, Marmara University. Istanbul / Türkiye
https://orcid.org/0000-0001-7445-4599

Corresponding Author:
Ezgi Sancaroğlu Yavuzer, ezgisancaroglu@gmail.com

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Abstract

Newborn screening through heel-prick blood sampling is a routine public health intervention in Türkiye. However, in recent years, a growing number of parental refusals have led to legal disputes, raising questions about decision-making on behalf of children, legal basis and obligation of the interventions, and the protection of children's best interest. This article examines the legal and ethical dimensions of heel-prick newborn screening in Türkiye, with a particular focus on Constitutional Court decisions and their implications for public health policy, parental rights, and protecting the child's best interest. Using a descriptive legal-ethical analysis, the article reviews four recent rulings by the Turkish Constitutional Court concerning parental refusals of heel-prick testing. The analysis considers these cases within the broader context of the principles of legality, legitimate aim, proportionality, and the best interests of the child. Comparative legal examples from international jurisprudence are also discussed. The Court upheld the legitimacy of the Newborn Screening Programme and recognized the state's duty to protect child's health. However, it also acknowledged legal ambiguities, the lack of explicit statutory mandates requiring parental compliance, in particular. The contradiction between providing a formal mechanism for refusal and subsequently overriding those refusals through court orders highlights a gap in legal coherence. To ensure consistency, transparency, and respect for both parental

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autonomy and child's welfare, Türkiye must revise its legal and administrative framework for newborn screening. Explicitly defining the mandatory status and scope of heel-prick testing is essential to strengthening public trust and upholding children's health rights within a democratic legal order.

Introduction

Newborn screening programmes are systematic public health initiatives designed to prevent permanent harm and improve the quality of life in children through the early detection of hereditary metabolic and endocrine disorders [1-4]. These programmes involve multiple stages, including health education, sample collection, laboratory analysis, and post-result clinical follow-up, and require the coordinated efforts of various institutions and healthcare professionals [1-3]. Their effectiveness depends not only on technical proficiency but also on the reliability and ethical integrity of their implementation. Because false-positive or false-negative results can have serious consequences for both individuals and families, continuous monitoring and evaluation of newborn screening programmes are essential to maintaining trust and efficacy [2].

In Türkiye, the National Newborn Screening Programme, administered by the Ministry of Health, exemplifies this systematic approach. Each year, millions of newborns are screened for conditions such as phenylketonuria, congenital hypothyroidism, biotinidase deficiency, cystic fibrosis, spinal muscular atrophy, and congenital adrenal hyperplasia [5]. The scope of the screening programme extends beyond clinical and laboratory testing to encompass critical ethico-legal and administrative dimensions, including sample quality, the efficiency of information systems, and the effectiveness of follow-up mechanisms [1-3]. These additional components reflect the programme's broader aim of safeguarding both individual and public health in a comprehensive manner.

The origins of newborn screening can be traced back to small-scale initiatives launched in Europe during the 1960s for phenylketonuria (PKU) [1-3,6]. A significant breakthrough occurred when Guthrie introduced a low-cost and practical method using dried blood spot (DBS) testing, which involved collecting a few drops of blood from the heel [4,7]. This innovation was soon followed by Dussault's development of a radioimmunoassay method for detecting congenital hypothyroidism, significantly broadening the scope of early diagnosis [8]. By the late 1990s, the introduction of tandem mass spectrometry revolutionized the field by enabling the simultaneous detection of 40-50 disorders from a single blood sample [3,6,8,9].

The expansion and institutionalization of newborn screening programmes have been guided by clear scientific and ethical standards. The criteria proposed by Wilson and Jungner in 1968 remain the foundational principles for evaluating and implementing population-based screening initiatives [10]. These criteria emphasize the importance of understanding the natural course of a disease, the feasibility of early intervention during its asymptomatic stage, the use of simple, reliable, and cost-effective testing methods, and the availability of appropriate follow-up and treatment for individuals with positive results. Together, these principles continue to inform the design and evaluation of modern newborn screening programmes worldwide.

Türkiye's first systematic newborn screening programme was launched in 1986 for phenylketonuria, through a collaboration between Hacettepe University Faculty of Medicine and the Ministry of Health [5,6]. By 1990, the programme had expanded to cover all provincial centres. In 2006, it was renamed the "Neonatal Screening Programme" with the inclusion of congenital hypothyroidism screening [11]. Over the following years, the scope of the programme expanded further with the addition of

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biotinidase deficiency (2008), cystic fibrosis (2015), congenital adrenal hyperplasia (2017), and spinal muscular atrophy (2022), bringing the total number of screened conditions to six [11].

Today, this initiative operates under the Newborn Metabolic and Endocrine Disease Screening Programme, administered by the Ministry of Health. Conditions such as phenylketonuria, congenital hypothyroidism, biotinidase deficiency, cystic fibrosis, congenital adrenal hyperplasia, and spinal muscular atrophy are routinely screened. Heel-prick blood samples collected at healthcare units across the provinces are sent to Provincial Health Directorates and then forwarded to central laboratories in Ankara and Istanbul. The analysis results are subsequently communicated back to the provinces. Infants with suspicious results are referred to relevant specialist clinics for further evaluation. Scientific advisory boards established for each condition support programme monitoring and evaluation, helping to protect approximately 4,500 children annually from adverse health outcomes [11].

Despite its public health achievements, the programme also raises growing ethical and legal concerns. Alongside its clinical effectiveness, debates have emerged around parental consent, the *de facto* mandatory nature of the procedure, the protection of personal health data, and the potential secondary use of biological samples. These concerns intersect with core ethical principles such as individual autonomy, parental authority, public interest, and the best interests of the child. As such, they prompt not only a reassessment of public health policies but also a broader reflection on the constitutional limits of state intervention in family and personal decision-making.

These ethical tensions have increasingly found their way into the legal domain. Individual applications submitted to the Constitutional Court of the Republic of Türkiye demonstrate that these issues are now part of judicial review [12-16]. In particular, the Court's rulings on public health interventions—such as heel-prick testing and compulsory vaccination conducted without parental consent—offer important precedents on how constitutional rights are balanced against the principle of the child's best interests. In this article, we examine the Constitutional Court's decisions concerning heel-prick blood collection in the context of newborn screening programmes. Our aim is to clarify the evolving legal framework that governs these practices and to propose recommendations for aligning them more closely with the ethical principles.

This study aims to examine the Constitutional Court's decisions on heel-prick blood sampling within the framework of newborn screening programmes in Türkiye, focusing on two of the central principles of bioethics: autonomy and beneficence. By analyzing how the Court balances individual rights, parental authority, and the best interests of the child, the study explores the legal and ethical legitimacy of medical interventions carried out without parental consent. The objective is to contribute to a broader reassessment of newborn screening programmes—beyond their technical and clinical effectiveness—by critically engaging with their ethical foundations and the evolving constitutional framework that governs them.

Materials and Methods

To explore the legal and ethical dimensions of heel-prick blood sampling within Türkiye's newborn screening programme, we conducted a focused document analysis of relevant Constitutional Court rulings. Individual application decisions were identified through systematic searches of the Constitutional Court's official database and the Legalbank decisions archive, using keywords such as "heel prick," "newborn," "newborn screening," "family doctor," "health centre," "child health measure," and "neonatal screening."

All relevant rulings delivered between 2012 and 2025 - the period following the introduction of the individual application mechanism - were reviewed to ensure comprehensive coverage. Relevant

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legislative and administrative texts were identified through keyword searches ("neonatal screening," "heel prick test," and "child health measure") in the Legalbank database and on the official legislation portal, *mevzuat.gov.tr*. These legal documents provided the basis for evaluating the constitutional and statutory frameworks surrounding heel-prick testing. Our analysis focuses on how these decisions engage with key bioethical principles—particularly autonomy and beneficence—and how they reflect the tension between individual rights, parental authority, and the state's obligation to protect child health.

As this study was based solely on publicly accessible court documents and did not involve human participants or identifiable data, it did not require ethical board approval or an application for ethics review.

Results

Our document analysis identified four individual applications submitted to the Constitutional Court of the Republic of Türkiye concerning heel-prick blood sampling conducted as part of the national newborn screening programme. These cases include applications by Muhammed Ali Bayram (2014/4077, 29 June 2016), Haydar Ali Bayram (2014/4255, 22 November 2017), Uğur Naki Yüreğiçakal (2020/22948, 19 December 2023), and Abdullah Tarık Kotay (App. No: 2021/1876, 6 June 2024). Each decision provides insights into how the Court interprets and applies constitutional principles—particularly the right to bodily integrity under Article 17—in the context of early childhood health interventions.

The Constitutional Court's **first** decision on heel-prick testing was issued in *Application No. 2014/4077*, concerning Muhammed Ali Bayram, making it the earliest and most foundational of these rulings. This decision has since served as a precedent for subsequent cases [12]. In this case, the newborn's parents refused both vaccination and heel-prick testing, and their refusal was formally documented. Following this, the Mersin Family Counselling Centre Directorate applied to the Mersin 2nd Children's Court, which issued a health protection measure in accordance with Article 5 of the Child Protection Law No. 5395. The applicants objected to the decision, arguing that neither vaccination nor heel-prick testing was legally mandatory, that the timeframe for implementation had expired, and that their child was in good health.

The objection was reviewed by the Mersin 3rd Children's Court, which rejected it. The court emphasized that vaccinations are effective in preventing infectious diseases and associated complications, and that newborn screening through heel-prick testing is essential for the early diagnosis of congenital conditions that, if left untreated, could lead to irreversible harm. In response to the parents' claim that the deadline for testing had passed, the court clarified that venous blood sampling could still be performed up to one month after birth. Concluding that both interventions were in the best interests of the child, the court upheld the health measure decision.

The applicants then brought the case before the Constitutional Court, which accepted it for review. Although the intervention had not yet been carried out, the Court found that the applicant faced a real and personal threat to bodily integrity and thus agreed to examine the merits of the case under Article 17 of the Constitution.

In its evaluation, the Constitutional Court acknowledged that both vaccination and heel-prick testing, when performed without parental consent, constituted an interference with the child's right to the protection and development of their material and spiritual existence. The Court noted that for such an interference to be constitutionally valid, it must satisfy the requirements of legality, legitimate purpose, necessity in a democratic society, and proportionality. However, it limited its review to Article 17 (right to bodily integrity) and did not consider the application under other relevant constitutional

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rights, such as privacy (Article 20), family life (Article 41), or freedom of religion and conscience (Article 24).

Regarding the vaccination component of the intervention, the Court found the legal basis insufficient. It ruled that Article 5 of the Child Protection Law No. 5395 lacked the predictability required by the principle of legality, as it did not clearly define the type, scope, or conditions of such health measures. Similarly, the Court found Articles 57 and 72 of the Public Health Law No. 1593 and related Ministry of Health circulars inadequate to justify mandatory vaccination, noting that only the smallpox vaccine was explicitly mandated by law. The Court referenced its earlier *Halime Sare Aysal* -childhood vaccination rejection case- decision[1] to support this interpretation. Based on this reasoning, the Court concluded that despite the intervention serving a legitimate public health aim, the condition of legality was not met due to the absence of a clear, specific, and foreseeable legal basis. Therefore, the health measure pertaining to vaccination was ruled to have violated Article 17 of the Constitution. This ruling reinforced the principle that even well-intentioned public health interventions must rest on explicit legal authority when they interfere with fundamental rights such as bodily integrity.

In contrast, the Court found the legal basis for heel-prick testing more robust. Articles 3 and 151 of the Public Health Law No. 1593 were deemed too general to serve as a legal foundation for this specific medical intervention [17]. However, the Court accepted Article 3 of the Health Services Basic Law[2] No. 3359—which provides for "measures to identify those at risk by subjecting newborns to necessary tests for metabolic diseases"—alongside Ministry of Health Circulars No. 2006/130 and 2014/7 [11,13], as sufficient to satisfy the legality requirement in the case of heel-prick testing.

Further supporting the proportionality of the measure, the Court noted that heel-prick testing was carried out only once, with the possibility of repetition under limited conditions, and that detailed procedural safeguards were outlined in administrative regulations. As no concrete harm to the applicant's health was identified and the procedure served a legitimate public health purpose, the Court concluded that the measure was necessary and proportionate in a democratic society. Consequently, it ruled that the heel-prick procedure did not violate Article 17 of the Constitution.

This decision established a key legal and ethical precedent. In subsequent cases involving heel-prick testing, the Constitutional Court explicitly cited the *Muhammed Ali Bayram* decision and reaffirmed its reasoning. As we show in the following cases, this initial ruling shaped the Court's evolving jurisprudence on the balance between public health obligations and individual rights in the context of newborn screening.

The **second** application concerns Haydar Ali Bayram (born on 1 November 2013), in which the healthcare institution that delivered the baby requested a heel-prick blood sample. However, the parents refused, citing the absence of a legal obligation to comply [14]. Consent was also withheld for a second attempt to collect the sample on 14 November 2013. Following this, the Mersin Family Counselling Centre Directorate of the Ministry of Health applied to the Mersin 1st Children's Court, requesting that the child be placed under health care. With its decision on 11 December 2013, the court ordered the implementation of a health measure for the child in accordance with subparagraph (d) of the first paragraph of Article 5 of the Child Protection Law No. 5395, dated 3 July 2005. A formal notice was issued to the family for the enforcement of the decision, and law enforcement officers accompanied officials to their residence. However, the parents physically obstructed the execution of

[1]Constitutional Court of the Republic of Türkiye. Application of Halime Sare Aysal [Plenary], App. No: 2013/1789, Decision Date: 11 November 2015.

[2]Republic of Türkiye. *Sağlık Hizmetleri Temel Kanunu* (Basic Law on Health Services in Turkey) (Law No. 3359, adopted 7 May 1987). Official Gazette. 15 May 1987;(19461).

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the court order. During this process, the family filed an objection to the health measure decision. The case was subsequently reviewed by both the Mersin 4th Heavy Penal Court and the Mersin 2nd Children's Court, each of which rejected the objection.

Following these events, information about the resistance encountered during the enforcement of the decision, along with the criminal complaint filed with the prosecutor's office, was submitted to the Mersin 1st Juvenile Court by the Provincial Public Health Directorate. Upon re-evaluating the case, the court revoked its previous health measure decision, citing the rulings of the 2nd Civil Chamber of the Court of Cassation (E.2014/149, K.2014/8841 and E.2014/33, K.2014/8131).

In the aforementioned Supreme Court decisions, health measures initiated by the Provincial Directorate of Family and Social Policies against parents who refused to vaccinate their children were reviewed. The rulings emphasized the principle of informed consent in medical interventions, stating that such consent must be obtained from the child's legal representative. The Court noted that decisions made without notifying or hearing the family are valid only for children under state protection. In cases where the child resides with their family, the legal representatives must be duly notified and heard, and any decision must be justified within that framework. Otherwise, decisions made without adequate investigation or adversarial proceedings are considered unlawful.

On these grounds, the health measure previously issued by the Mersin 1st Children's Court was revoked, and the intervention was not carried out. Consequently, the Constitutional Court ruled that there was no longer a reason to continue with the application, as the lower court's decision had been annulled and the intervention had not been implemented. The case was therefore dismissed.

Thirdly, in Application No. 2020/22948, *Uğur Ali Naki Yüreğıçatal* [15], the newborn was invited by staff at the family health centre to receive vaccinations and to provide a repeat heel-prick blood sample. However, the parents refused to consent to either procedure. While no official record was made regarding the vaccination, the refusal to allow a repeat heel-prick sample was documented, with the parents stating that the initial sample had already been taken at the hospital after birth and that a repeat was unnecessary.

Following this refusal, the Kayseri Provincial Health Directorate confirmed that the first heel-prick sample had indeed been collected within 48 hours of birth, but noted the parents' objection to a repeat sample. In response, the Kayseri Provincial Directorate of Family, Labour and Social Services submitted a request to the Kayseri 2nd Children's Court, seeking to impose a health measure under Article 5 of the Child Protection Law No. 5395. On 21 July 2020, the court ruled in favour of the health measure, asserting that the parents' refusal clearly conflicted with the child's best interests. The decision was supported by relevant case law from the Court of Cassation and legal opinions issued by the Ministry of Health's Legal Advisory Office.

Challenging the decision, the applicants argued that the initial heel-prick sample had been obtained under proper conditions, that there was no medical necessity for a repeat test, and that the child had been subjected to physical coercion during the first procedure. Nevertheless, the Kayseri 1st Children's Court rejected the objection. After the final decision was officially communicated, the applicants filed an individual application with the Constitutional Court.

In its review, the Constitutional Court applied the same legal standards of legitimacy and legality as it had in the *Muhammed Ali Bayram* decision. However, in assessing proportionality and necessity in a democratic society, the Court focused on whether the second intervention was appropriate, necessary, and proportionate to the legitimate aim pursued. In this specific instance, the Court found that the initial heel-prick sample had been collected under acceptable conditions and noted that, under the Ministry of Health's General Circular No. 2014/7, a repeat sample is only warranted if the initial sample—taken 48 hours after oral feeding—is deemed invalid. Since no such indication existed in this

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case, the Court concluded that the justification for a second sample was insufficient. Accordingly, the Constitutional Court ruled that the health measure constituted a violation of Article 17 of the Constitution, which guarantees the right to the protection and development of one's material and moral existence.

Fourthly, in Application No. 2021/1876, filed by *Abdullah Tarık Kotay* [16], staff at the family health centre requested a heel-prick blood sample as part of the postnatal screening process. However, the parents refused to consent to the procedure. They also declined routine baby monitoring and mandatory vaccinations, submitting a signed petition to the family health centre, which was duly documented by the relevant health personnel.

In response to this refusal, the Kayseri Provincial Health Directorate reported that heel-prick blood sampling is mandatory under the National Neonatal Screening Programme and formally recorded the parents' non-compliance. Subsequently, the Kayseri Provincial Directorate of Family, Labour and Social Services applied to the Kayseri 2nd Children's Court, seeking the implementation of a health measure pursuant to Article 5/1(d) of the Child Protection Law No. 5395. The court accepted the application, concluding that the parents' refusal was incompatible with the child's best interests, and referenced supporting legal opinions from the Court of Cassation and the Ministry of Health. Drawing on the approach adopted in the *Muhammed Ali Bayram* decision, the Constitutional Court evaluated the application within the scope of Article 17 of the Constitution, determining that the intervention was lawful and served a legitimate aim.

Continuing its analysis, the Court turned to the question of proportionality. It emphasized that no concrete harm had been identified to the applicant's health. With respect to the parents' argument concerning risks posed by the COVID-19 pandemic, the Court noted that this issue had not been raised during the initial objection to the health measure. Furthermore, no specific allegations had been made regarding insufficient precautions by the health authorities. Therefore, the Court found no basis to conclude that the pandemic created an individualized risk significant enough to render the intervention unnecessary or disproportionate.

Based on this evaluation, the Constitutional Court ultimately held that the intervention had a clear legal foundation, pursued a legitimate public health objective, and met the criteria of necessity and proportionality in a democratic society. Accordingly, it ruled that there had been no violation of Article 17 of the Constitution.

Table 1 provides an overview of the four Constitutional Court decisions concerning parental refusal of newborn heel-prick screening in Türkiye, summarizing the key aspects of each case, including the local court decision, grounds for the family's objection, and the Constitutional Court's ruling.

Table 1. Overview of Constitutional Court Decisions concerning parental refusal of Heel-Prick Screening.

Applicant Name	Date of Decision	Reason for Application	Final Decision	Relevant Article, Law And/or Ethical Principle
Muhammed Ali Bayram	June 29, 2016	Health measure ruling issued following parents' refusal of heel-prick blood sampling and vaccination; the family rejected the procedure on the grounds that the heel-prick period had expired.	It was ruled that Article 17 of the Constitution had not been violated.	Article 17 of the Constitution; Article 3 of the Fundamental Law on Health Services No. 3359; Ministry of Health Circulars No. 2006/130 and 2014/7 (principles of legality, legitimate aim, necessity in a democratic society, and proportionality).

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Applicant Name	Date of Decision	Reason for Application	Final Decision	Relevant Article, Law And/or Ethical Principle
Haydar Ali Bayram	November 22, 2017	Health measure ordered after parents refused heel-prick screening; reported to the prosecutor due to the family's obstruction. The lower court later revoked the decision.	Case dismissed: the lower court withdrew its decision, the intervention was not carried out, and the Constitutional Court decided to dismiss the application.	In the renewed lower court decision, emphasis was placed on the principle of informed consent (see Court of Cassation, 2nd Civil Chamber decisions E.2014/149, K.2014/8841 and E.2014/33, K.2014/8131).
Uğur Ali Naki Yüreğiçatal	December 19, 2023	Health measure ruling issued following parents' refusal of repeated heel-prick blood sampling.	It was ruled that the right to the protection and development of material and moral existence under Article 17 of the Constitution had been violated.	Article 17 of the Constitution; Ministry of Health Circular No. 2014/7 (failure to ensure the principles of proportionality and necessity in a democratic society). When the first heel-prick sample is taken more than 48 hours after birth, there is no legal basis for a second sampling. From an ethical perspective, the principle of non-maleficence may take precedence over the lack of expected benefit.
Abdullah Tarık Kotay	June 6, 2024	Health measure ordered after parents refused heel-prick screening, infant follow-up, and mandatory vaccinations, citing the COVID-19 period.	It was decided that Article 17 of the Constitution had not been violated.	Article 17 of the Constitution; Article 3 of the Fundamental Law on Health Services No. 3359; Ministry of Health Circulars No. 2006/130 and 2014/7 (principles of legality, legitimate aim, necessity in a democratic society, and proportionality). It was also noted that there was no claim regarding the failure of the healthcare institution to take necessary COVID-related precautions, which was relevant to the assessment of proportionality.

Key legal and ethical considerations in court decisions

The Constitutional Court's decisions on heel-prick testing highlight the complex legal and ethical terrain surrounding newborn screening practices in Türkiye. While these cases share a common concern—balancing public health measures with constitutional rights—they also expose tensions between parental authority, state intervention, and child welfare. In this section, we explore the broader implications of the Court's rulings under three interrelated themes: *decision-making on behalf of children*, *the legal basis and obligation for medical interventions*, and *the protection of the child's best interests*. Through this analysis, we aim to contextualize the judgments within the principles of biomedical ethics and public law, and to assess their potential impact on future policy and clinical practice.

Decision-making on behalf of children

In cases where children lack the capacity to make decisions regarding medical interventions, their parents, healthcare providers, or, in some instances, the courts may act on their behalf [19]. Parents are generally presumed to be the most appropriate decision-makers for their children. Since children are not capable of autonomous decision-making, those acting in their stead are expected to do so in the child's best interests [20,21]. However, when it is argued that parents are not acting in accordance with those interests, their authority may be overridden. In such situations, the parental duty to protect the

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child's well-being is considered to outweigh the parental right to make decisions, ensuring that the child's right to health protection takes precedence [22].

Mandatory childhood vaccination programmes, for instance, illustrate how a child's right to healthcare or the broader imperative to protect public health can override the parental right to raise their child according to personal beliefs [21,22]. While parents may accept the risks of forgoing vaccination for themselves, declining it on behalf of their child—and thereby exposing the child to preventable harm—is not regarded as an absolute right [23,24]. The court decisions concerning heel-prick blood sampling for newborn screening, which are the focus of this article, reflect similar ethical and legal reasoning. While parents retain the right to make healthcare decisions for their child, it remains essential that they are adequately informed about the procedure and that their consent is obtained prior to the collection and use of heel-prick blood samples. For this purpose, the "Newborn Screening Programme Heel Prick Blood Collection Information and Refusal Form" [25], available on the Turkish Ministry of Health's website, is used to inform parents and document either consent or refusal.

In the Constitutional Court cases we examined, several parents submitted written refusals using this official mechanism. In response, authorities argued that the parents had failed to make a decision that adequately protected the child's health and, on that basis, petitioned the children's courts to authorize a health protection measure under Article 5 of the Child Protection Law No. 5395, permitting the collection of the heel-prick sample [18]. This procedural pattern recurred across all four cases reviewed by the Constitutional Court.

Similar tensions between parental authority and the child's right to health have been addressed in various legal systems, offering useful comparative insights. For instance, in Canada, the Supreme Court's decision in *B.(R.) v. Children's Aid Society of Metropolitan Toronto* affirmed the state's right to override parental religious objections to ensure necessary medical treatment, underlining that parental rights are not absolute when a child's life or health is at risk [26]. Similarly, in Australia, State Supreme Courts hold "*parens patriae*" authority to consent or refuse treatment on behalf of a child, particularly if parental refusal is not in the child's best interests [27]. These cases collectively reinforce the principle, also reflected in Turkish Constitutional Court rulings, that while parental decision-making is important, it may be overridden -both lawfully and ethically- to protect the child's fundamental right to health.

Legal basis and obligation

In its decision on *Muhammed Ali Bayram* [12], the Constitutional Court acknowledged that heel-prick blood sampling had a legal basis and deemed the relevant regulations sufficient under the principle of legality. The Court observed that paragraphs (1) and (7) of Article 3, first clause, of Law No. 1593 [17]—which assign the Ministry of Health the responsibility to facilitate childbirth, reduce child mortality, and protect the health of children and youth—are general in nature and do not, on their own, constitute a specific legal basis for heel-prick testing. However, the Court found that Article 3 of the Basic Law on Health Services, which stipulates that "...measures shall be taken to identify those at risk by subjecting newborn babies to the necessary tests for metabolic diseases...," together with Ministry of Health Circulars No. 2006/130 [11] and No. 2014/7 [13], provides an adequate legal foundation for the procedure. Within this framework, the Court affirmed that heel-prick blood sampling meets the requirements of legality.

This precedent later informed another Constitutional Court decision on heel-prick sampling: The Abdullah Tarık Kotay case [16]. In its judgment dated 6 June 2024, the Court cited the Muhammed Ali Bayram decision during its legality review and again concluded that the procedure fulfilled the conditions set by the principle of legality.

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Nonetheless, requiring parental consent for heel-prick sampling introduces practical challenges in implementation. The use of the Newborn Screening Programme Heel Prick Blood Sampling Information and Refusal Form—which allows parents to formally refuse the procedure—complicates enforcement. If existing regulations are interpreted as rendering the procedure mandatory, parental refusal may be considered unlawful, thereby obligating families to comply. However, the current legal and administrative framework does not explicitly define the procedure as mandatory. Consequently, it remains unclear why parents are granted the legal option to refuse the procedure by completing the form if such a refusal is later judged to constitute a failure to safeguard the child's health. This presents a fundamental inconsistency: either the form lacks legal validity, or the legal justification for overriding parental refusal is questionable from the standpoint of legal coherence.

Comparable issues have emerged in other jurisdictions. In the United States, all states operate mandatory newborn screening programmes, but legal disputes have revealed inconsistencies in consent practices. In 2019, in *Kanuszewski v. Michigan Department of Health and Human Services*, the Sixth Circuit ruled that collecting newborn blood without parental consent could violate privacy rights, despite statutory requirements for screening [28]. Similarly, in the Netherlands, the Supreme Court ruled in 2010 that while initial screening was lawful, the long-term storage of residual samples required specific legal authority to satisfy the principle of foreseeability under the European Convention on Human Rights [29]. In Australia, while mandatory newborn screening is broadly accepted, legal scholars emphasize the need for precise legislative definitions to ensure transparency and legal consistency as the scope of screening programmes evolves [30].

To recap, in cases where the law prescribes a mandatory intervention, relying on parental refusal to delay or obstruct the procedure, and subsequently seeking a court order to authorize it, undermines the intended efficiency and preventive function of such public health measures. If heel-prick testing is to be obligatory, the law must state this clearly to satisfy the principle of legality. Absent such clarity, legal ambiguity will persist, and court proceedings may become necessary in each instance of parental refusal, thereby eroding the consistency and effectiveness of the programme.

Protecting the best interests of the child

Another prominent issue in discussions on this topic is the protection of the best interests of the child. In cases where parental refusal would result in harm to the child, competent authorities may override that refusal [31]. For example, in situations involving rabies exposure—where the child's life is at risk—it is argued that healthcare professionals have a legal and moral duty to ensure that the child is vaccinated, regardless of whether parental consent is provided [32]. In such circumstances, the principle of autonomy in Western medicine—namely, basing decisions on the individual's right to choose—is subordinated to the child's best interests. Thus, parental autonomy is restricted, and courts, acting as representatives of society, are tasked with determining the course of action that best serves the child [33]. Yet it is not always clear how the best interests of the child are defined or protected in different contexts, such as in the case of heel-prick blood sampling.

Thus it becomes clear that the tension between parental refusal and state intervention demands not only legal, but also ethical, consideration. Health risks that may affect a child's future, if preventable through early action, create both individual and societal responsibilities. When parental autonomy is restricted in favour of the child's right to health, the legitimacy of the intervention must rest not only on consent but also on demonstrable benefit. In this context, the long-term consequences of diseases detectable through newborn screening—affecting the individual, family, and society—make the ethical justification for heel-prick testing even more compelling. Demonstrating the concrete benefits of early treatment at both the individual and societal levels reinforces the legitimacy of the practice in terms of both the bioethical *principle of beneficence* and constitutional standards.

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Untreated metabolic and endocrine disorders not only have irreversible effects on an individual's quality of life but also increase the long-term burden on the healthcare system. For example, if left untreated, biotinidase deficiency can cause a wide range of symptoms, including seizures, developmental delays, respiratory issues, dermatological lesions, and hearing and vision loss [34,35]. However, early diagnosis during the neonatal period and timely initiation of biotin treatment can prevent these complications and support healthy development in affected children [34–36]. Similarly, in individuals with undiagnosed phenylketonuria, impaired phenylalanine metabolism can severely impact brain development, leading to intellectual disability, epileptic seizures, and behavioural problems [37,38]. However, a low-phenylalanine diet initiated following early diagnosis can significantly preserve cognitive function and improve social adaptation [38].

Furthermore, if left untreated, congenital hypothyroidism can cause permanent neurological damage and severe intellectual disability. These adverse outcomes can largely be prevented through the early initiation of levothyroxine therapy. However, a review of studies published prior to the implementation of newborn screening for hypothyroidism found that the average intelligence scores of treated children were still lower than those of their healthy peers [39]. It is also estimated that each 1-point decrease in average IQ results in a 1% reduction in lifetime earnings [40]. This underscores the importance not only of early diagnosis but also of the earliest possible intervention.

Moreover, in patients with cystic fibrosis, delayed diagnosis can lead to serious complications, including recurrent respiratory infections, pancreatic insufficiency, growth retardation, and reduced life expectancy 41,42]. Standard treatments—such as respiratory physiotherapy, enzyme replacement, and nutritional support—can significantly improve quality of life when initiated early. Moreover, early access to gene modulation therapies, where genetically appropriate, can be decisive in altering the disease course [43]. It has been shown that at least half of cystic fibrosis patients in Türkiye are eligible for these next-generation treatments [44].

In the early stages, the most important benefit of diagnosing spinal muscular atrophy (SMA) through newborn screening is that it allows treatment to begin before symptoms appear [45-48]. Children diagnosed and treated through screening have been shown to have a significantly higher likelihood of reaching key motor development milestones—such as independent sitting and walking—compared to those diagnosed after symptom onset [45-48]. For example, one study reported that 90.9% of children identified through screening were able to sit independently, and 63.6% were able to walk, whereas these rates were only 14.7% in children diagnosed after symptoms appeared [42]. It has also been demonstrated that children treated presymptomatically may remain asymptomatic and exhibit normal or near-normal development during follow-up [45-47]. Moreover, early treatment—particularly in severe forms of SMA—can prevent serious complications such as respiratory failure and early death, and reduce the likelihood of permanent disability [45,46]. Newborn screening facilitates rapid referral to specialists and timely initiation of disease-modifying therapies. It also empowers parents to make informed decisions and access multidisciplinary care services more effectively [49,50]. Early diagnosis and treatment reduce the likelihood of severe disability and the need for long-term intensive care, thereby lowering overall healthcare costs [51].

Another example is congenital adrenal hyperplasia (CAH), in which early diagnosis through newborn screening offers significant health benefits. It enables the prompt initiation of hormone replacement therapy, thereby preventing adrenal crises that can be fatal in newborns and infants [52–54]. It also facilitates the management of salt-wasting forms of CAH, reducing the risk of severe dehydration and shock [54,55]. In non-classical forms, early diagnosis can prevent or mitigate hyperandrogenism, which may otherwise lead to early puberty, virilisation, and related complications [56]. Children who are diagnosed early and treated appropriately demonstrate normal cognitive and executive functioning compared to their healthy peers [57]. Moreover, early diagnosis helps minimise emotional stress,

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social stigma, and behavioural problems for both children and their families—issues commonly reported in cases of late diagnosis [58].

Discussion

In August 2024, a decision[3] issued by the Kars Family Court on 20 August 2024 drew strong criticism from medical associations, including the Turkish Medical Association, for its statements that "the purpose of the heel prick test is unclear" and "its nature is uncertain." In response, several professional bodies issued public statements highlighting the benefits of newborn screening tests [59–62]. The Turkish Medical Association emphasized that the heel prick test—carrying negligible risk—enables the early detection of serious conditions such as phenylketonuria, thereby safeguarding children's lives and preventing severe and irreversible outcomes like intellectual and physical developmental delays [59]. These statements underscore the critical public health function of heel prick testing in protecting children's health.

In a petition submitted to the Ministry of Health, the Turkish Society of Pediatric Nutrition and Metabolism affirmed that heel prick screening is universally accepted, grounded in robust scientific evidence, and constitutes an essential part of preventive health services [60]. The petition stressed that untreated metabolic disorders such as phenylketonuria and biotinidase deficiency can result in irreversible neurological damage, psychomotor retardation, behavioral disorders, hearing and vision loss, dermatological issues, metabolic crises, and even death. Early diagnosis and treatment can prevent these outcomes, protect infant health, and reduce the long-term burden on society. The Society also noted that the absence of legal sanctions—despite the inclusion of the statement "I accept all legal and criminal responsibility" in the refusal forms—has contributed to the growing number of refusals.

Similarly, the Turkish Thoracic Society emphasized that heel-prick screening is part of a child's right to a healthy life, as well as to early diagnosis and treatment. It warned that court decisions based on unscientific reasoning jeopardize children's right to health and underscored the danger of parents arbitrarily refusing medical interventions on behalf of their children. The Society asserted that the right to refuse treatment belongs solely to the individual and can only be exercised by parents in cases where no treatment is available or where the benefit to the child is ambiguous or disputed. The Society also called for the introduction of clear legal regulations to safeguard the health rights of infants [61].

Echoing these concerns, the Ethics Committee of the Turkish Medical Association stressed the duty of both the state and adults to protect children from harm, consistent with the principle of the child's best interests enshrined in the Convention on the Rights of the Child. The Committee reminded healthcare professionals that if a legal guardian refuses or obstructs medically recommended treatment that is beneficial to the child, the physician has an obligation to apply to the relevant legal authorities to overturn that decision [59].

In its Muhammed Ali Bayram decision, the Constitutional Court acknowledged that the heel-prick procedure carried out without parental consent constituted an interference with the child's right to protect and develop their material and spiritual existence, as guaranteed by Article 17 of the Constitution. To determine whether this interference was constitutionally legitimate, the Court evaluated the measure not only under the principle of legality (discussed previously), but also through the lens of legitimate purpose, necessity in a democratic society, and proportionality. Within this framework, the Court recognized the Newborn Screening Programme as pursuing a legitimate aim, stating [12]:

[3]Further details can be accessed via the news source: https://www.bbc.com/turkce/articles/c2078xl5ny2o.amp

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> "The Newborn Screening Programme aims to prevent mental retardation, brain damage, and irreversible harm by screening all newborns for congenital hypothyroidism, phenylketonuria, biotinidase deficiency, and cystic fibrosis, thereby reducing the economic burden on society; to raise public awareness about consanguineous marriages; and to initiate appropriate treatment in diagnosed babies to prevent complications arising from these diseases, thus helping them reach a certain level of intelligence. In this context, it is clear that the programme in question serves the legitimate aim of protecting children and, consequently, public health."

Despite affirming the legitimacy of the aim, the Court emphasized that taking a heel-prick blood sample without parental consent still constitutes an interference with an individual's fundamental rights. Therefore, the procedure must be proportionate to the aim pursued; the interference must not undermine the essence of the right or render it meaningless. The Court stressed the need to strike a fair balance between individual rights and the public interest.

The Court's further assessment found that the procedures conducted under the Newborn Screening Programme are limited in scope and designed solely for diagnostic purposes. It noted that the Ministry of Health's Circular includes detailed regulations on the purpose, timing, site, preparation, collection process, and post-procedural handling of blood samples, all of which aim to minimize risks to infant health. It also acknowledged efforts to ensure regular training of personnel in line with the Circular and its guidelines.

Finding no indication of adverse effects on the child's health or allegations of harm, and given the substantial benefits to both individual and public health, the Court ruled that the heel-prick procedure was necessary and proportionate in a democratic society. Consequently, it concluded that Article 17 of the Constitution had not been violated. This reasoning was reaffirmed in the Court's later decision in the Abdullah Tarık Kotay case, which also found no violation of Article 17 [16].

In contrast, the Haydar Ali Bayram decision did not involve a ruling on whether collecting a heel-prick sample against parental objection violated Article 17. Instead, the Constitutional Court dismissed the case on procedural grounds, following the lower court's revocation of the original health protection order. The Mersin 1st Children's Court's reversal was based on prior rulings by the Court of Cassation (Court of Cassation 2nd Civil Chamber, E.2014/149, K.2014/8841 and E.2014/33, K.2014/8131), which emphasized parents' rights to participate in and be informed during legal proceedings involving their children [14]. These rulings held that a health protection measure imposed without such procedural safeguards—particularly without proper notification and hearing of the parents—was unlawful. While these decisions primarily concerned procedural integrity and accurate identification of parties, they underscored the importance of upholding parental rights unless compelling evidence supports limitation of those rights for the child's protection.

In application No. 2020/22948, Uğur Ali Naki Yüreğıçatal, healthcare authorities had collected a heel-prick sample at birth and later requested a second sample. After the parents refused, the Provincial Directorate of Family, Labour and Social Services sought and obtained a court-ordered health measure. The family then submitted an individual application to the Constitutional Court. In reviewing the case, the Constitutional Court found that authorizing a second heel-prick test without adequate justification violated Article 17 of the Constitution. Although the Court reaffirmed the legitimacy of heel-prick testing without parental consent, citing the earlier Muhammed Ali Bayram case, it determined that the specific conditions justifying a second test had not been met. The Court observed that the initial sample had been collected in accordance with Ministry of Health Circular No. 2014/7, but the justification required for a second sample under that same Circular had not been demonstrated. As such, the health protection order was found to lack sufficient legal basis, and the Court ruled that the child's constitutional rights had been violated.

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Limitations

The main limitation of this study is its exclusive focus on Constitutional Court decisions, which may not fully represent the diversity of lower court or administrative practices. Furthermore, as a document-based analysis, it does not include empirical data from healthcare providers or families, which could enrich the ethical and practical interpretation of the findings.

Conclusion

This article explores the legal and ethical dimensions of heel-prick newborn screening in Türkiye, focusing on recent Constitutional Court rulings that highlight the tension between parental authority, state responsibility, and protecting the best interests of children. The Court has consistently recognized the legitimacy of the National Newborn Screening Program, affirming its alignment with public health objectives and the principle of legality. However, these rulings have also revealed significant ambiguities in the current legal and administrative framework. Notably, there are no explicit statutory provisions that make the procedure mandatory. This creates a reliance on judicial intervention when parents refuse consent.

The coexistence of official refusal forms and subsequent legal actions that override those refusals creates a contradiction that undermines legal coherence and predictability. This discrepancy complicates implementation for healthcare professionals and risks eroding public trust in preventive health programs. The findings also demonstrate that, although the state has a legitimate interest in safeguarding children's health, it must do so through clear, proportionate, and rights-respecting mechanisms. Furthermore, as illustrated by international jurisprudence, state interventions that override parental decision-making must be carefully justified, particularly in situations that do not pose an imminent threat to life or health.

Taken together, the analysis underscores the urgent need for regulatory clarification and legal reform. To ensure ethical consistency and prevent unnecessary judicial involvement, Türkiye’s health authorities and lawmakers must explicitly define the scope, limits, and obligations associated with newborn screening. Clearer legal provisions would better support families and professionals, reinforce the program's credibility, and more effectively uphold children’s right to health within a democratic, rights-based framework.

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