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► To cite this version:

Pauline Oviedo, Yannick Jaffré, Bruno Danic, Stéphane Mazières, Jacques Chiaroni. Impact of societal and legal context on the blood supply of African-ancestry populations in Western countries: A review of practices and the French example. *Vox Sanguinis*, 2022, 10.1111/vox.13326 . hal-03695255

HAL Id: hal-03695255

<https://hal.science/hal-03695255>

Submitted on 14 Jun 2022

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REVIEW

Impact of societal and legal context on the blood supply of African-ancestry populations in Western countries: A review of practices and the French example

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Funding information

Etablissement Français du Sang (EFS), the French blood agency

Abstract

In Western countries, blood supply agencies encounter impediments in providing blood groups defined as rare or of interest, notably for sub-Saharan African ancestry (SSAA) recipients. To establish warning levels and anticipate future blood needs, an estimate of the current carriers of rare blood groups, both potential patients or donors, is crucial but complex. Indeed, if the strict needs can be estimated in medical terms, the modalities of blood product collection must be considered from an interdisciplinary perspective, at the interface of biological data and social norms. Here, we aim to understand how legal choices and a set of representations of otherness may influence the supply of rare blood for SSAA populations. After examining these issues, considering different norms and limits that govern French society, we compare this data with those of four Western countries facing the same difficulties (United States, United Kingdom, Italy and the Netherlands). This work began as part as the reflections of Social Lab, an institutional programme created by the French Blood Establishment (EFS). How can we effectively improve the qualitative blood coverage for SSAA populations? There is no unique solution, but there are many more or less effective answers. Comparison across countries reveals a strong influence of the socio-political histories and ethical choices before technical and medical considerations. We consider that an institutional policy is required to resolve recruitment issues of SSAA donors sustainably. Lastly, we introduce a working group called the EFS Social Lab, which aims to set up a monitoring mechanism for donors and societal trends to make blood donation effective.

KEYWORDS

anthropology, donor motivation, donor recruitment, donors, ethics, social norms

Highlights

- Specific societal contexts of each countries affect differently blood donation, particularly in terms of the ethical and legal representation of 'otherness'.

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- Rather than subsuming populations with African ancestry into a single ethnic group, an in-depth knowledge of those populations involved is required to improve blood donation.
- The creation of Social Lab, a French institutional initiative to use medical humanities sciences in the monitoring of donors and social trends, will help in this endeavour.

WHY A CLOSE ATTENTION TO SUB-SAHARAN AFRICAN ANCESTRY POPULATION?

Globalization contributes to the deterritorialization of populations, both as cause and effect. Today, about 3.4% of the world population, totalling 258 million international migrants, do not live in their places of birth [1]. Migration routes follow the former colonial political areas and present linguistic communities and idealize the Western countries [2–4]. In France, migrations originate mainly from Africa (47.5% of immigrants), of which 18.3% are from sub-Saharan Africa [5]. Here we refer to the French sub-Saharan African ancestry (SSAA) population, the diversified immigrants and descendants of sub-Saharan origin who live in metropolitan and overseas France. This population was and is motivated to migrate by a multitude of motives, and they have different administrative statuses (i.e., recent or long-term migration, permanent or temporary arrivals), nationalities and the number of generations since arrival [6, 7]. Socially, the entanglement between the country of origin, ages, administrative status and access to citizenship builds an extremely complex patchwork of infinite cultural and political variations [8]. However, though diverse in their identities and backgrounds, the French SSAA population shares biological links with the sub-Saharan African sub-continent. The hiatus between the almost immobile time of genetic transmission and the extreme variability of social situations is not without consequences for blood transfusion. It generates haematological management problems related to migration, explicitly concerning rare blood groups (RBGs).

In France, RBGs have a frequency of less than 1/250 in the general population and no alternative for transfusion compatibility by another blood group. RBGs refer to the following situations: (1) rare blood phenotypes per se, defined by a private, low-frequency or absence of a public antigen (e.g., the Dantu MNS25 antigen, the 700 series or the lack of RH:18 and 19) and (2) relative rarity, related to the uneven geographical repartition of phenotypes [9]. If all human populations are considered, SSAA populations are more exposed to rarity consequences after migration to Western countries. The genetic diversity of African populations is the highest of any population in the world, mainly caused by a longer pre-historic incubation followed by drip out-of-Africa expansion. Moreover, SSAA populations are largely carriers of red cell abnormalities in response to selective pressures of malaria, such as membrane protein polymorphisms, enzymatic disorders and haemoglobin variants [10]. Notably, one of the latter is responsible for sickle cell disease requiring sustained and complex transfusion therapy [11, 12]. The healthcare challenge results from

this tension between necessity and scarcity, between, on one hand, a demographic increase of SSAA populations in Western countries with specific haematological characteristics, and, on the other hand, blood product supplies under pressure and sometimes insufficient to handle some distinctive pathologies and the daily health events (childbirth, accidents and surgical procedures).

To ensure self-sufficiency in rare blood products in response to growing demand, it is crucial to have adequate stocks of the targeted blood and, therefore, upstream recruitment of SSAA donors. Effective recruitment intricately involves medical and social dimensions. Here we want to focus on the social aspect, which influences both supply and demand of blood products. Availability of rare blood products requires anticipation and requisite expertise to assess future needs from quantitative and qualitative perspectives. We seek to understand how legal choices and representations of otherness may influence the supply efficiency of rare blood for the Afro-descendant population and what resources organizations have to deal with these availability issues. Finally, we present the strategy adopted by the French Blood Establishment (EFS) to improve availability based on social trends.

THE DIFFICULTIES OF AN ETHNIC CENSUS AND COMMUNITY DONOR RECRUITMENT

Foremost, to correctly assess the level of the stocks of RBG concentrates required, we must evaluate the needs and human resources present in France and thus have demographic data tagging ‘African ancestry’. While it is neutral and easy to define biologically, it is more complex to handle sociologically and legally. In France, the legislation stipulates that ‘it is forbidden to process personal data revealing the alleged racial or ethnic origin [...]’ [13]. Meanwhile, by decision no. 2007-557 DC of 15 November 2007 (act relating to the control of immigration, integration and asylum), the French Constitution Council prohibits ‘the processing of personal data that directly or indirectly reveals the racial or ethnic origins of individuals and the introduction of variables of race or religion into administrative files. This applies to the identification directory of natural persons’. Only studies on the measurement of the diversity of origins, discrimination and integration based on objective data such as geographical origin or nationality before French nationality, or subjective data, such as the ‘feeling of belonging’, are authorized. While these legal and ethical precautions help in avoiding various forms of discrimination, they complicate the assessment of the size of populations with RBG. If a character-based census of individuals is per se possible, it would indirectly reveal the

ethnic origin, which is illegal as stipulated before. Moreover, it would not distinguish the double descendants of African immigrants—homozygous Africans—from those with an African surname but from admixed ‘domino couples’ who are genetically heterozygous and so are unlikely to carry an RBG. In practice, there are indirect ways to obtain an estimation. EFS is allowed to register the birthplace of the donors and point out the geographical origin through a computer flag. This makes it possible to implement additional biological screening to search for rare phenotypes and genotypes.

Therefore, RBG needs estimation relies on the ‘rare blood network’, a dedicated process that monitors data related to the delivery of phenotypes considered to be of interest, the number of sickle cell patients (10,000 currently with 400 births per year), the number of active blood donors with phenotypes of interest and the stocks of frozen red blood cells. However, this piecemeal research does not allow for a precise estimate of current and future needs. It is possible to operate legally, but on the margins and by benevolent tracking of donors. This discordance between ethical precautions and the lack of biological precision to identify low-frequency blood phenotypes restrains proactive policies for RBG needs.

The other main limitation of blood product availability is blood collection and, hence, the modalities of donation. In Marseille, where we operate [14–16], in France [17], but also in Europe [18, 19] and in other Western countries [20–27], studies have documented the blood donation determinants of various SSAA populations and highlighted low participation of both occasional neo-donors and recurrent blood donors. Furthermore, the representation of the body and its tissues (blood and organs), as well as the normative systems (e.g., misplaced belief that religions discourage blood or organs donation) are essential but in no way subsume all the factors determining the behaviour of donors.

Indeed, donor behaviour includes socio-political dimensions linked to migration, such as cognitive and practical difficulties to give blood in case of linguistic precariousness and administrative irregularity. The positive correlation between blood donation, social inclusion and even the acquisition of citizenship has previously been shown [15, 26, 28, 29]. If the act of giving inscribes the person in a relationship that includes a counter-gift in return, or at least a recognition of the act [30], what reciprocity or recognition a person might expect when he/she is precisely not admitted to reside and live in the political space where he/she stays? A young Senegalese street vendor we met in Marseille says: ‘I wonder how they’ll see it... because a black man who comes to donate blood... they don’t look at you [...]. It’s an apprehension maybe, [...] and already you want to do a good deed, and people look at you strangely, and finally, you wonder ...’ [15]. We must recognize that in many ways, access to information, the possibility of presenting identity documents during control without fear of getting into trouble, linguistic ability and citizenship are essential determinants of donation.

In summary, the donation of RBG is thus constrained, in France, by a specific configuration articulating ethical rules and, largely, situations of social, linguistic and administrative precariousness of migrant populations or those recently settled in France.

COMPARE THE INFLUENCE OF LEGAL AND ETHICAL CHOICES ON THE EFFECTIVE SUPPLY FOR RBG

In this review, we perform a reflection on the French supply system of compatible blood products for SSAA populations considering French history and its legal and cultural components. However, many Western countries are subject to the same worldwide phenomenon of population mobility and undergo blood supply issues. The decisions taken in four different countries—the United States, the Netherlands, the United Kingdom and Italy—depict an interweaving of historical, legal and ethical dimensions specific to each country and a diversity of responses to blood collection problems.

As illustrated in Table 1, these four countries encounter the same under-representation of SSAA individuals in their donor population. However, the presence of the SSAA population in these countries and their possible estimation are not subject to the same historical and social background. For example, despite descending from forced migration [50] and a history of racial segregation policies, African-Americans are demographically and statutorily constitutive of the American nation. In this country, an ethnic census with self-determination allows the possibility to know the ‘racial’ origin of Americans. Conversely, Italy was a country of emigration until the 1970s, and then of transit for African populations. It was only in the early 2000s that it also became a host country for immigrants from Eastern Europe, North Africa mainly, but also South Africa [51, 52]. Identification of immigrants or descendants of immigrants is based on citizenship [53]. British migration flows reflect its colonial past (i.e., significant proportion of immigration is from Commonwealth member countries and former territories of the British Empire from West Indies [Antilles], the Indian subcontinent and Africa) [54], as in France. But similar to the United States, the United Kingdom became a multicultural societal model where self-determination has indicated the ethnic origin since the 1991 census [53]. However, this approach has two limitations. First, it remains subjective and, second, the categories proposed in the census (e.g., nationality, region, subcontinent continent, skin colour) are not always standardized. In this regard, the Dutch case is interesting, which combines a recognition of its ethnic diversity to fight against discrimination, but based on the birthplace (or the birthplace of parents) and not on self-determination as in the United Kingdom [55]. The Netherlands is an example of mixed migration of Africans, on the one hand, of American origin with flows from former colonies of the Dutch Empire and, on the other hand, from recent migrations from sub-Saharan Africa for political, humanitarian or economic reasons.

Through the prism of their own historical and legal background, countries tend to conceive adapted solutions. Issues of rare blood supply are tangible in the United States, where African-Americans represent a substantial part of the needs due to RBG and a high prevalence of sickle cell disease (1/500 births) [23]. Compared to European countries, the bibliography on African-Americans blood donation is abundant and long-standing [36, 56–60]. In addition to the barriers systematically found (lack of awareness and knowledge,

TABLE 1 Overview of SSAA populations and donors and rare blood programs in France, United States, United Kingdom, Italy and the Netherlands

| | SSAA individuals in general population ^a | SSAA individuals in donor population ^b | Ethnicity recognition in population [31] | RBD programs | RBD registration | Research and awareness on RBD ^b |
|----------------|---|--|---|---|---|--|
| France | 4.48% of African immigrants (1.85% SSA) [5] | 1.5% donors born in SSA ^c | By citizenship, birthplace and citizenship of parents for descendants of immigrants | National since 1980s (RBD database since end of 1960s) [32] | ~13,000 RBD and patient registered (2016) | <ul style="list-style-type: none"> National campaigns with Social Lab Studies about determinants of blood donation with community campaigns [14–16] University events but unspecific to SSAA Local campaigns with territorial approach |
| United States | 13% of Black or African-Americans [33] | 3% [33] | By self-determination: decennial census with self-determined ethnicity categories | National since 1998 (RBD database since 1960s) [34] | 51,000 active RBD (2013) [35] | <ul style="list-style-type: none"> States campaigns Local, religious, community campaigns [36, 37] Studies about deferral factors [38, 39] Studies about determinants and events on university [40] |
| United Kingdom | 3.3% in England and Wales (Black, African, Caribbean or Black British) [41] | ~1% [41] | By self-determination: decennial census with self-determined ethnicity categories and citizenship, birthplace | National program since 1952 [42] | ~2000 active RBD (2016) | <ul style="list-style-type: none"> Studies about determinants of blood donation for SSAA population awareness [43]: Nationals campaigns Local, religious, community campaigns Communication initiative Target events University events |
| Italy | ~1.6% of African immigrants (less than 1% of SSA) [44] | n/a | By citizenship: birthplace and citizenship of parents | Regional programs in Lombardy (LORD-P 2005) and Sicilia (2010) and local ones [45] | LORD-P: ~9300 RBD registered [46] | <ul style="list-style-type: none"> n/a |
| Netherlands | 3% (SSAA residents) [31] | n/a on SSAA population but only 1% from minority groups [47] | By citizenship: birthplace and citizenship of parents | National program [48] RB units frozen and stored since 1970s; Sanquin Bank of Frozen Blood since 2006 | 900 active RBD | <ul style="list-style-type: none"> Studies about determinants of blood donation for SSAA population [18, 31, 49]. |

Abbreviations: n/a, not available; RB, rare blood; RBD, rare blood donor; SSA, Sub-Saharan Africa; SSAA, sub-Saharan African ancestry.

^aAs legislation differs, it refers to several options (census/estimation and nationality/ethnicity). Therefore, comparisons between them should be carefully considered. Diverse possibilities are specified.

^bResearches about donor recruitment only (not immunohaematology aspects).

^cIncluding French territories (Guadeloupe, Martinique, Guyana, Reunion island and Mayotte).

technical barriers), more sporadic obstacles include distrust of health institutions, ethnic discrimination and lack of empathy due to a lack of identification with the receiver. Determinants of blood donation in the United States are well known, and further studies will enhance the accuracy of the expertise, like for European SSAA populations. But just as we cannot summarize all the variability in the perception of SSAA individuals under the umbrella of a single African culture, the representations of blood donation for African-Americans cannot be invariably applied to all other SSAA populations. In contrast to the United Kingdom, which has had a dedicated rare blood programme for over half a century [42], addressing RBG issues is new for Italy, and so is the policy for SSAA blood donation. However, despite recent attention to the issue, Italy has local programmes, plus two regional programmes in Lombardy and Sicily [45]. Consequently, the country counts many active rare blood donors. Lastly, the studies of blood donation in the Dutch population of Surinamese, sub-Saharan and Caribbean ancestry have highlighted the lack of awareness and practical constraints as the main impediment [18, 31, 49]. As in France, where blood donation is possible only in French, language can be an obstacle in the Netherlands because it is done only in English or Dutch. The Netherlands still has only a few SSAA donors compared to the general donor population. As it happens in other countries, importation of compatible blood for African blood phenotypes is required, and therefore European and international collaboration is indispensable.

At the European scale, the European Blood Alliance initiated the Missing Minorities (MIMI) project to understand low donation determinants among minorities in Europe. It demonstrates the increased awareness of European countries regarding blood donation by people of African ancestry. However, government-wide management of rare blood remains at an early stage [47]. All the studies recently conducted at the European level highlight the relevance of this topic [61]. Ultimately, blood drive policies are different. It appears that their definitions are probably more influenced by their socio-political histories and ethical choices rather than by technical and medical considerations alone. This multidisciplinary approach is essential and has resulted in concrete actions.

EFS SOCIAL LAB: A FRENCH INTENT TO IMPROVE BLOOD SUPPLY OF SSAA POPULATIONS

Although legislation evolves to suit societies and their needs, it is unlikely that the limitations regarding the ethnic origins of individuals will change soon in France, restricting leeway for anticipating needs. Current socio-political debates on blood donation mainly concern blood donation at 17 years of age or the restrictions for men who have sex with men. Despite this, it is still possible to work on new donor recruitment.

In 2018, the EFS created an internal working group called 'EFS Social Lab', made up of around 15 EFS professionals (e.g., MD, communicators, researchers). EFS Social Lab monitors the donors and societal trends to identify topics that may impact blood donation

(e.g., the donor recognition in a voluntary blood donation system, the conversion from whole-blood donation to plasma donation, the evolution of commitments among young people, and, as we have just described, blood donation in minorities). The final objective is to give recommendations based on evidence and not just perceptions to guide the EFS executive direction in strategic decision making.

On this basis, the work began with a bibliographic inventory supplemented by surveys, as well as masters and PhD studies in connection with the academic world. Three organizational deficiencies stood out: the insufficient and non-procedural orientation of the recipients and their siblings to donation, the non-specific collection policy and donor relationship, and a welcome system insufficiently attentive to diversity. The EFS Social Lab made recommendations based on 10 points.

To optimize the existing system and define a specific programme for rare blood:

1. Review current procedures, check their range of application and identify their weaknesses.
2. Review the current collection practices for recruiting rare donors (RDs).
3. Define RBG donors and proceed with adequate information depending on the frequency of the phenotype in the population.
4. Define a specific donor care.

To create a network of rare blood referents including doctors from the blood collect:

5. Identify one or several 'rare blood' referents in each regional blood transfusion centre.
6. Produce an annual activity report for each regional blood centre.
7. Create a dynamic network of rare blood referents based on sharing and feedback.

To evaluate the efficiency of recruitment actions:

8. Define a methodology and a protocol to apply to guarantee the validation of the effectiveness of the actions.

To help recruit rare blood donors for blood drive managers:

9. Create a reference tool to help them identify the places to collect and the validated recruitment actions to implement.

To train EFS employees and partner volunteers:

10. Create specific training at a national level.

WHICH SOCIAL APPROACH TO BLOOD DONATION?

For some socio-political spaces, blood is a marketable product. For others, it has a human and non-mercantile value that cannot be

indexed to a price. It also expresses how much giving blood reflects the symbolic representations of oneself, inherent in identity, transmission and filiation. It refers to the sedimentation of the memory of events in which blood was brought to the fore: the contaminated blood affair, the mad cow disease and HIV. Finally, it shows how much the act of giving is part of an expectation of recognition, not necessarily pecuniary, but identity-related.

Indeed, the willingness to donate inscribes the donor in a social community, and if accepted, the donation confirms membership to this community. And this is probably why sexual or territorial minorities are fighting for a right to give, which is synonymous with a confirmation of legitimate social existence. 'The idea that the gift must be returned presupposes that the other is another self that must act like me, and this gesture in return must confirm to me the truth of my gesture, that is, my subjectivity [...], men confirming to one another that they are not things' [62].

But donor recruitment requires the aptitude to mobilize citizens living in evolving societies where social consideration stands above in a multicultural and diverse globalized world. The crucial achievement is to translate academic and practical knowledge into concrete and successful actions. Research and action must be conducted simultaneously and over the long term. It is important to involve the collection operators as early as possible in the development of the experimentation protocols. This is the only way to ensure their future integration into operational procedures for long-term effectiveness. We are increasingly using the human and social sciences to understand the motives of social actors, to dialogue with various populations and to improve the quality of relations with donors at blood drives. However, although they have proven to be effective, these actions aimed at better understanding the contexts of our medical actions are difficult to sustain, as in the case of our anthropological study [14]. We consider, however, that an institutional policy is necessary to patiently build social and health interfaces that will allow us to improve the recruitment problems of the SSAA populations.

We cannot go any further in the framework of a brief exploratory review but merely underline that ensuring the functional chain of blood from the evaluation of needs to the setting up of an alert system, the availability of blood products, and the coherent use of rare bloods requires the construction of an epistemological and technical interdisciplinary space between medical and social sciences.

ACKNOWLEDGEMENTS

Pauline Oviedo received a PhD studentship award as study manager (2018–2021) from Etablissement Français du Sang (EFS), the French blood agency. P.O. analysed the literature, wrote the manuscript and reviewed it. Y.J. wrote the first draft of the manuscript and reviewed it. B.D. reviewed and revised the manuscript. S.M. and J.C. supervised the research and critically reviewed and revised the manuscript.

CONFLICT OF INTEREST

The authors declare no conflict of interests.

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How to cite this article: Oviedo P, Jaffré Y, Danic B, Mazières S, Chiaroni J. Impact of societal and legal context on the blood supply of African-ancestry populations in Western countries: A review of practices and the French example. *Vox Sang*. 2022.