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ORIGINAL ARTICLE

“It has to somehow permeate to the public”: expert views on the solidaristic potential of Israel’s National genomic biobank initiative

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Abstract

The 2018 Digital Health Initiative (DHI) implemented by Israel included the establishment of a national biobank. Establishing a national biobank was clouded in ample rhetoric of solidarity promising scientific and economic progress, and financial benefits. To assess the potential of these promises, we conducted 15 semi-structured interviews with experts with a management, health or political background from Israel over a one-year period. Applying a data solidarity framework to the insights gained from the interviews, we concluded that a national biobank indeed offers great potential for medical progress under the condition that data use is transparent and mechanisms for access are clear. In contrast, we estimate that claims on economic and financial benefits are less certain and depend on controversial ideas like the trickle-down effect. To strengthen the beneficial effects of a national biobank, we recommend policymakers adhere to data solidarity to avoid misappropriating solidarity.

Keywords Biobanks · Health Policy · Solidarity · Misappropriated Solidarity

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Introduction

Biobanks are as much social endeavors as they are technological ones, with social institutions and interactions evolving concurrently with technical implementation. Israel's "Digital Health Initiative" (DHI) was established in 2018[1] as a huge promise for "the public good" in terms of both health and wealth. It promoted the foundation of a national biobank that was expected to benefit the Israeli public. These benefits to the public were portrayed as a national economic engine of growth and as significantly improving medical care. This endeavor could be described as a form of "solidarity" (Prainsack and Buyx 2017) where people participating in the same medical framework give up some of their personal biological data and receive in return medical as well as economic benefits, either individually or collectively as a society. But can these promises be fulfilled?

Our study focuses on the views on the establishment of a national biobank in Israel of experts in the field, within the wider context of the Israeli healthcare system. We conducted 15 semi-structured interviews over a one-year period with experts from Israel. The Digital Health Initiative (DHI), that encompasses the establishment of a national, publicly operated biobank, is plagued by an institutional lack of transparency regarding its financial aspects. We, therefore, examine how this lack of clarity and transparency is perceived and explained by those Israeli experts in the context of biobanking.

We aim to answer the following question(s): What benefits and limitations of this specific biobank do experts expect? Who benefits directly? According to these experts, should and could there be a mechanism to share those benefits with the public that contributes the data? In other words, to what extent do these experts consider biobanks through a solidaristic prism? Finally, how could a solidaristic perspective inform policymakers in designing and managing a framework such as the Digital Health Initiative (DHI) and more specific, the establishment of a national biobank in Israel? We start with a short overview of the research on biobanks and Israeli biobanks especially. In this section, we will also introduce the concepts of solidarity in bioethics and "data solidarity" (Prainsack et al 2022a; 2022b). We will show how this relates to the introduction of biobanks in Israel and possible pitfalls to avoid.

State of the art

Biobanks

The new biobank integrates the existing unique digital datasets of medical data of Israeli citizens, such as blood types, genomic data, and disease history among others. "Israel's Psifas [mosaic, in Hebrew] will integrate more than 20 years longitudinal

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[1] https://www.gov.il/he/departments/policies/des3709_2018.

community and hospitals EHR [electronic health records] data with WGS [whole genome sequencing] from hundreds of thousands consented patients. This unique clinical-genomic database with easily accessed patient population will be recruited for prospective research focused on early detection and improved treatment of many maladies"[2]. The Israeli Health Maintenance Organization (HMOs) together with Hospitals collected these data in the last 20 years. Donors then complete this national treasure with biological samples. Portraying the merger of all these different data sources as no less than a medical, economic, and social revolution (Fisher and Rosenhek 2022), according to the Ministry of Health in 2022, the ethnic "mosaic" of the Israeli population[3] will benefit. The initiative was budgeted at 898 million NIS for 5 years.[4] Governmental estimates predicted annual 12 billion NIS revenues for the Digital Health plan, of which the future Psifas biobank will constitute a central component[5]. Yet, only in 2023—5 years after the declaration of the initiative—Psifas was launched. However, no transparent mechanism for the regulation of its establishment and operation—including benefit sharing (among health institutions, the state, the pharma industry, and the public)—has been published to this day. It remains unclear what future profits should be gained, and how should they be shared with the public—both the general public and the donors whose medical data and biological samples form the foundation of the resource.

This situation seems unusual as other countries with operating biobanks have established transparent mechanisms such as oversight or supervising committees (Hallinan 2021a, b).

Biobanks store large collections of biological samples and associated data from volunteer participants for use in biomedical research, often recognized as a strong tool in the promotion of precision/personalized medicine. Due to their perceived potential, national biobanks have been established worldwide. Because of their public and participatory nature, a central concern is *cui bono*—who benefits?

In other words, is it a "population-based" biobank or a "public" biobank? This was the title we gave to our first report written in the context of the Van-Leer led project on biobanks, where we compared the regulation and governance of various large-scale biobanks in other nations.[6] In short, the report explores whether they are 'publicly managed' operating for the public good, or if they only use data from the population. The comparison demonstrated varying degrees of public participation in biobanks' establishment and management. In most cases, the donors do not receive any direct personal benefits for their participation. We then published (Raz and Hashiloni-Dolev 2022) a study titled "Donating with eyes shut" that discussed the motivations, expectations, and dissonances of Israeli biobank donors. We found

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[2] Prof. Gabi Barabash, Psifas CEO, 2023; see https://www.icpermed.eu/en/mosaic-initiative-a-launchpad-for-personalised-medicine-1116.php.

[3] see https://www.gov.il/he/Departments/General/psifas.

[4] *The Marker* says 922 million NIS over 5 years; see https://www.themarker.com/news/health/2018-03-25/ty-article/0000017f-db72-df62-a9ff-dff7f35b0000.

[5] "Netanyahu's plan: Researchers and private companies will have access to public health data," *The Marker*, see https://www.themarker.com/news/health/1.5937990.

[6] *anonymized for peer-review*.

that the donors expressed low levels of trust in the state, the HMO and the pharma companies, often acknowledging the inability to protect donors' privacy in today's world. Many did not expect any personal return for their participation. The willingness to donate to the biobanks was motivated by notions of advancing science and supporting public health. Deciding to donate while accepting that they cannot trust the system and will not personally benefit from it was a dissonance that was solved by a "trusting method" (Au et al. 2024) of overlooking and hoping for the common good. Here we continue our exploration by discussing the views of Israeli biobank experts, aiming to get more insight through their account of these themes and what can be done to reconcile expectations and the factual situation.

Biobanks as 'solidaristic institutions'?

The DHI was hardly debated in the public and the media. It also received little attention in academic research (Tamir 2020; Fisher and Rosenhek 2022). An important and exceptional example for deliberation was that of Israeli sociologist and social activist Barbara Swirski, who published in 2020 a critical opinion on the website of the Adva Center, entitled "Data about our bodies must benefit us."[7] She argued that it is not enough to view the planned biobank as a growth engine; it must serve as an engine of equality and benefit the health not only of the few who can afford to pay huge sums of money for new medicines that are not part of the basket of health services. She also suggested several recommendations, including legislating that health data are the property of the donors, who are entitled to share in findings and treatments derived from their data.

Swirsky draws a stark contrast between commercialism and public good in the operation of the biobank. She fears that such public-private cooperation will result—as Filc and Davidovitch indicated (2016)—in rapid processes of privatization that only exacerbate inequalities in healthcare. And yet, the Israeli health system has a commitment to solidarity from its beginning in the pre-state period (Clarfield et al 2017) to the clear statement on mutualism as a core value in the preamble of the National Health Insurance Law in 1995. This commitment, although eroded under the global hegemony of New Public Management (NPM) practices (Cavalcante 2019; Ferlie 2017; Gruening 2001), still bears prospects for biobanks to exercise a more solidaristic approach. But what is solidarity in the context of biobanking?

As mentioned, political actors implementing the Israeli Biobank framed this institution as an endeavor profiting the whole population. This rhetoric painting ample promises for the future, masks the fact that the actual medical outcomes for the benefit of society are uncertain and might be distant at best. The emphasis on solidarity is used to weaken expectations for personal benefits (Bühler et al 2018). Solidarity in bioethics, as understood by Prainsack and Buyx, although not placing explicit emphasis on the expectation of personal benefits, does not exclude the possibility of direct or indirect future benefits. In their working definition, solidarity is understood as an "enacted commitment to carry 'costs' (financial, social, emotional

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[7] https://adva.org/wp-content/uploads/2020/03/Big-Data.pdf.

or otherwise) to assist others with whom a person or persons recognize similarity in a relevant respect" (2017: 52). Through the recognition of similarities with the addressee of our solidarity, we implicitly posit the possibility of finding ourselves in a similar situation at some point. Our present solidarity, therefore, reflects an aspiration that someone else would do the same if we would be in this specific situation.

Furthermore, Prainsack and Buyx identify "three tiers of solidarity" (2017: 54) classifying the structural level of different solidarity practices. They discern between interpersonal practices involving solidarity enacted between individuals, a group level where whole association of people enact solidarity either with an individual or another group, and finally the legal tier describing top-down implemented practices of solidarity like social security systems represent (ibid.) Sally Scholz, an American political theorist, calls this type of solidarity "civic" solidarity (2021: 27). Although both of these definitions are constructed from a different perspective, they describe the same phenomenon: A solidaristic practice that was created as institutional arrangement. As a biobank is ingrained in the healthcare system, one of the typical examples of this kind of civic, or legal tier solidarity, it is itself a form of civic solidarity. Considering the rhetoric of solidarity used to implement the biobank, the authors want to stress the "epistemic responsibility" (Pongiglione 2024) that postulated solidaristic practices are actually effective. We consider solidarity as a key element of any society, but especially in the case of democratic societies. Burelli and Camboni (2023) show that Solidarity persisted because it holds a vital role in the quotidian functioning of democratic societies (ibid.). They understand solidarity "as an aetiological function of society" (ibid.) bridging the gap between the relational aspect of solidarity between people and the institutional aspect of solidarity between people, society and the state. Without solidarity as cohesive force, societies dissolve as people will be less collaborative and more competitive. Therefore, solidarity imposes normative duties on democratic societies to foster it through measures such as redistributive systems or accessible healthcare. This condition is always important, but it is especially important for a state to not undermine the solidarity principle for its own survival.

Biobank activity is associated with complex ethical, legal, and social concerns. These revolve around privacy, risk, benefits, and trust (Raz and Hashiloni-Dolev 2022). As Hoeyer (2008) claims, informed consent is often purposefully portrayed as a magic solution to all these concerns, and he calls to move beyond informed consent to better assess and address the governance of biobanks. One major source of anxiety is commercialization and its associated issues of benefit sharing and fairness. The drive for profit generation through biobanks-activity challenges their claims for "pure" health-promoting motivations, thereby raising questions about their accountability (Hoeyer 2008). Additionally, the constant promotion of the Israeli Biobank coated in solidarity rhetoric demands clear criteria to justify these claims.

An emerging debate around the question of "Data Solidarity" (Prainsack et al 2022a; 2022b) in a broader bioethical context, provides a possible path to follow. This more abstract concept provides a framework for a risk assessment of whether data should be shared, and if so, with whom and under which conditions. They rely on "three main pillars: Facilitating good data use (pillar 1); preventing and mitigating harm (pillar 2); and returning profits to the public domain (pillar 3)" (ibid). This analysis of data use results in the creation of a matrix combining value and risk, with four more or less distinct categories of data use: Type A data use could facilitate the creation of benefits with high public value under low-risk conditions; Type B data use could facilitate the creation of benefits with low public value under a high-risk setting; Type C data use could facilitate the creation of benefits with high public value under high- risk conditions; and, finally, Type D data use could facilitate the creation of benefits with low public value under low-risk conditions (ibid.). This raises the question of what type of data use biobanks correspond to. Our continued investigation of expert experiences in the biobank field in Israel will provide valuable insight into this question, adding to our understanding from previous research.

The tension between solidaristic claims and the profit motive is reflected by a growing body of evidence pointing to some public concerns. The public fear that the commercial interests reduce the trust in the benefit-sharing of biomedical research (Raz et al. 2020). Additionally, biobank documents, aimed at potential donors, lack details characterizing the exact nature of public-private interactions, and, thus, the resulting distribution of benefits and risks remains unclear (Samuel et al 2022). Covering up these economic and business aspects of biobank-based research is also facilitated by promoting donors' commitment to the endeavor for example, under the rhetoric of solidarity.

One such concern is that pharmaceutical companies taking advantage of the availability of genomic biobank data will continue to reproduce unequal access to expensive treatments (Samuel et al 2022). Therefore, the question that needs to be addressed, according to Hoeyer (2008), is "how the interests of the donors can be accommodated by the basic organization of the research" (442–3). However, mechanisms to ensure this are not yet in place. As Mitchell and Waldby (2010: 333) stress, "biobanks should be held to public account in terms of their claims to further the collective interests of their donors and the public interests of the citizens more generally."

The idea of "data solidarity" (Prainsack et al 2022a; 2022b) could be a helpful guiding principle to foster solidaristic mechanisms in the realm of biobanks. If the concerns we described are not dealt with, the DHI and the actors implementing it risk creating a situation of "Parasitical Solidarity" (Weiss 2025; Shults 2024). Parasitic Solidarity describes a mechanism where proposed or established solidaristic practices do not fulfill the "Epistemic Requirements of Solidarity" (Pongiglione 2024), i.e., the solidaristic practice does not help to alleviate the postulated problem. Pongiglione analyzes the anti-sweatshop movement and certain actions within the wider climate-protests (ibid.). Her analysis shows how, even if in good faith, supposedly solidaristic practices can be useless, or worse, harmful. Useless and harmful practices that are framed as solidaristic, supposed to help a certain "oppressed group" (Scholz 2021; Weiss 2025), and established top-down by an institution, are forms of "Parasitical Institutional Solidarity" (Weiss 2025). Such situations of Parasitical Solidarity, especially the institutional variant, risk the continuous alienation of the people navigating those institutions. In consequence, their trust in this very institution erodes. In the case of the Israeli biobank, the solidaristic motivation of willing donors, whether intentionally or unintentionally, risks misappropriation. Instead of delivering on the financial, economic and medical promises made, the operational model of the biobank further increases profits of companies controlling the pharmaceutical and healthcare business. Although a previous empirical study into the expectations of donors carried out by some of the authors showed that they "donated with eyes shut" (Raz and Hashiloni-Dolev 2022). In the long run such allegedly misappropriation of solidarity could create public rifts and distrust. This is a trend that isn't limited to the realm of healthcare, as the debate around the Israeli gas fund shows[8].

Methods

This study is based on semi-structured interviews. The interviewees are 15 stakeholders who—through their profession—are related to the field of biobanks from different angles: Researchers in the academia who serve on advisory committees of biobanks (3), people with management positions in local biobanks (5), people from the Ministry of Finance (2) and the Ministry of Health (2), bioethicists (3), and people in the field of medical entrepreneurship (7). There is an overlap of participants between categories explaining the difference between those numbers and the total amount of interviews. All of our interviewees are working and living in Israel. We do not provide more specific information relating to these people in order to ensure their anonymity.

Following IRB approval, we approached participants, identified through professional networks, via email. We then filled gaps to reach theoretical saturation using the snowball method. After receiving an explanation about the research, participants provided informed consent. Using semi-structured interviews, we probed their views on expected benefits, medical and/or financial, from biobanks and what they consider to be a fair distribution of those benefits. The authors constructed the interview guide following a review of the literature on biobanks complemented by the findings from our previous study on Israeli biobank donors (Raz and Hashiloni-Dolev 2022). The interviews were held in Hebrew between February 2022 and February 2023 using zoom and over telephone. They lasted 30–90 min and we transcribed them verbatim.

We coded the transcripts following a thematic analysis approach (Denzin and Lincoln, 1994). We identified emerging broad themes and subsequent subthemes and discussed them as a team to prevent the bias of a single rater and ensure validity and to some degree reliability. In periodical meetings, we discussed new findings along with their relevance to the identified codes, while agreeing on needed modifications

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[8] A somewhat equivalent situation exists in Israel regarding another national resource, that of natural gas, and the management of its profits. Benefits from the gas supplies of Israel are both public and private; they are public in the sense that it is after all a national resource, and it is private since it is at the hands of private entrepreneurs that are motivated by profit-making. To balance the tension between the two, a mechanism called "Fund for Israeli Citizens," also known as the "Wealth Fund" was legally established in 2014. For more see Fisher & Rosenhek 2022.

and reclassifications. The lead author, in accordance with the rest of the author team, then, interpreted these themes following principles of interpretative analysis (Prainsack and Pot 2021) applying a solidarity and data solidarity framework to assess the policy challenges faced by the introduction of a national biobank in Israel.

Findings

In this chapter, we will first present a short overview of the impression of our interviewees on whether the DHI and the establishment of a national biobank can fulfill the high aims of the three main promises made beforehand: Medical and scientific progress, financial benefits, and economical benefits. In the second section, we will further delve into what our interviewees identified as the possibilities and limitations of medical and scientific progress of such a biobank. Then, in the third section of this chapter, we will discuss what our interviewees describe as the possibilities and limitations of financial and economic benefits created by the establishment of a biobank. Finally, before interpreting and discussing these empirical findings, we will highlight what our interviews reaped on the problems of excessive promises.

Overview

The introduction of a national biobank in Israel could be a driver for medical and scientific progress as well as financial and economic benefits. This progress and these benefits were emphasized heavily in the promotion of the DHI. Depending on the distribution of these benefits within the wider population as well as the implementation of medical and scientific progress, the introduction of the national biobank in Israel could contribute to the expansion of solidarity practices in Israel. How to achieve a distribution enhancing solidarity in Israel depends on the nature of the expected benefits and progress as well as their actual scope. The costs of solidarity in the context of a biobank is quite obvious: People give up their biological information. In exchange, although on the institutional tier of solidarity, there has to be someone or a group of people with whom the person letting their biological information could have recognized similarity(ies) in order to develop a want to help this person (or this group of people). In other words, there has to be a benefit to actual people in Israel itself, ideally to a very large fraction of the population and at least more vulnerable people, not just the economic elite.

According to the experts interviewed, medical benefits, trough scientific progress, are the most likely to be obtained. Scientific research is dependent on a large data influx that would be immensely facilitated by a nationally organized biobank. We identified a widespread agreement between our interviewees on the advantages of such biobank sharing data with researchers and respective organizations:

> "Eventually, the product of the research is what the patient will gain." 10.03.22_anon

Medical benefits through scientific research are also complemented by expected financial and economic benefits for the population[9]. Although promoted as one part of the DHI's benefits, our findings indicate that there are no widespread expectations in our interviews of any meaningful financial benefits in the operation of a biobank itself:

> "None of these biobanks is becoming rich. Most of them are completely unprofitable, which is why only countries build them." 03.07.22_anon

Financial benefits could be derived of successful data usage by pharmaceutical companies developing new medical treatments and drugs, but this would not reach the biobank itself. These financial benefits are therefore more part of the economic benefits expected. Data collecting, data sharing, and the succinct data usage need a sophisticated economy around these processes. Therefore, the DHI will further expand job opportunities in the medical and research field, a traditionally high paying sector. Finally, the profit-driven environment of data brokering in healthcare settings is a source of concern for our interviewees.

In summary, the experts took an ambivalent position between highlighting the actual needs for biobank data for research and the realistic picture of expected benefits while navigating the hyperbolic rhetoric used in the political campaign beforehand. This ambivalence hints to some confusion on the side of politics to what a national biobank can realistically provide in added value. Additionally, it is also a sign of possible misappropriation of solidarity to blur unpopular effects of a national biobank. We will further discuss these two aspects of our findings in the next chapter.

Enabling medical progress as a solidaristic practice

As previously stated, the experts agreed on the fact, that biobank data will enable scientific progress, and, therefore, unlock medical benefits for everybody as discoveries are made and new treatments, testing tools, as well as drugs, are developed. These advancements then will generally improve healthcare for the Israeli population. While some provided tangible examples, others spoke of the promise of "high-level treatment" and "advancement of healthcare"; both of these are somewhat vague prospects. Nevertheless, experts from all categories, as the following is an instance of, stressed the importance of patient data and data sharing to enhance healthcare outcomes:

> "We can use all sorts of data to give better care for our patients, which is the only goal of our organization." 18.05.22_anon

The following interviewee—with a management position in one of the local biobanks—saw the establishment of biobanks as an opportunity to include

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[9] Financial benefits describe direct monetary remuneration, either for the state budget, the HMO budget or other involved actors such as donors. Economic benefits describe a more abstract development of economic indicators, such as GDP or quantity and quality of job opportunities among others.

under-represented populations, providing a more tangible example of healthcare advancements. Their inclusion could facilitate medical treatments better adjusted to the various needs of a genetically diverse population:

> “You know, this too is not taken for granted. But at least at the intentional level this should be a goal—appropriate representation of all sub-populations of the public.” 16.02.23_anon

This expert is not convinced that such benefits can be automatically reaped by the public. She stresses the need for carefully intervening in the process to guarantee potential benefits for all parts of society.

While this instance showcases critical thinking that questions the operation of biobanks and their efficacy, others were less critical of their management and goals. For example, some did not think any conflict exists between the for-profit pharmaceutical industry and the public good:

> “It’s a company that is making drugs for our well-being and our health. If we’re not going to give the drug companies the information, then we’re not going to get the drugs in the end.” 15.02.22_anon

Similar, some mentioned the possibility of indirect financial benefits culminating in medical benefits. In the case of biobanks belonging to HMOs, the HMO’s services could improve through financial earnings from the biobank’s activity as this interviewee—a bioethicist—suggests:

> “If it is a biobank belonging to an HMO and the profits from making the biobank accessible for research stay in the HMO and serve the HMO, then I don’t think it is much of a problem, with the condition that it has to somehow permeate to the patients. For example, money earned from making the samples accessible should be directed at improving the service and care, such as better availability of treatments. […] But the members of that HMO should feel the benefit also in that secondary sense and not only from the direct sense of the actual product of the research.” 16.03.22_anon

Consequently, financial benefits directly depend upon the actual profits generated by the operation of the biobank. However, as will be shown in the next section, a repeating claim was that such earnings are rather low. Without clear beneficiaries or tangible expectations, the question arises how to safeguard the solidarity principle.

Economic and financial benefit sharing as a solidaristic practice

The spectrum of answers regarding the question of economic and financial benefits for the population—that were marketed as a key objective for the establishment of a national biobank, alongside the advancement of health in Israel—was wide and included disagreements. A few respondents, despite their relation to the field, mentioned that until the time of the interview they hadn’t really given a thought to the economic aspects of biobanks. As the economic benefits took on a central role in the public presentation of the creation of a biobank, this lack of awareness is rather surprising. The establishment of a national biobank was accompanied by the idea that such an institution would generate substantial financial profits, eclipsing the role of facilitating scientific and medical progress that such data can play, we asked the interviewees specifically where the financial and economic profits should go. Should potential profits return to the state in general, specifically to the healthcare system, or more specifically, to the donors themselves? Again, some experts did not think about this question beforehand and, thus, were reluctant to answer. Others had more concrete albeit diverse answers.

Respondents with a financial profession referred to the economic benefits and saw them as the initiative's major public contribution. In their view, the highest value of the initiative would emanate from the advancement of the quality employment sector, which would create high-income positions:

> "The main goal is creating high-income employment. […] The donor eventually benefits as a citizen from the fact that an industry has been developed." 13.03.22_anon

Others referred to more focused desired economic gains for the healthcare system. However, many respondents claimed that unlike the common perception and advertisement of this field as rich with gains, biobanks, in fact, do not produce much or even any profit. They explained that the minor profits earned from making the data accessible for research by external bodies, only allow for their maintenance and the advancement of further research projects. Uncertainty around revenues barely covering high maintenance costs was a repeating theme. Participants described a predicament of costly sequencing processes and personnel salaries that are just covered by the fee paid by companies for accessing the biobank's services. This creates on-going concern for management members (and probably also employees) and may potentially lead to a conflict of interest. This interviewee—with a management position in one of the local biobanks—describes the operational model:

> "All the money coming into the research institute is invested in further studies, in human resources of researchers, statisticians, epidemiologists, doctors." 21.03.22_anon

In Summary, the promised economic benefits are not that clear. There seems to be a case for the creation of some high-income jobs, but the direct financial gain from the operation of a biobank cannot be confirmed to satisfaction by those working in such organizations.

Regarding the direct return of (financial) benefits to the donors, there was a broad agreement that such a mechanism would be impractical. Our interviewees used moralization and bioethical language. Some stressed the meaning of the term "donation," and referred to philanthropic or charitable ideals, therefore dismissing individual return to donors, as another interviewee with a management position in a local biobank sums up:

> “I don’t look at it in such a way of “on an individual level—what’s in it for me.” […] In my view, it’s a bit tunnel vision to look at it on an individual level.” 21.03.22_anon

Moreover, not giving back to the public in terms of economic benefits was legitimized by relying on the scientific ethos, claiming that medical research has always been done that way—in “conventional” clinical trials too:

> “Even if you participated in such research [a clinical trial] and if you received the placebo—no one guarantees that once a medicine makes it to the market you will get it. [...] So I don’t see any distinction between genetic research and any other research.” 16.02.23_anon

A recurring claim was that once a person knowingly donated, especially since it is an anonymous donation, there is no room for expectation for a personal benefit in return for the donation:

> “In my view, once the patients are willing to renounce any claim for the sake of benefitting medicine and if they are informed that it will be used also for commercial purposes, then I think that from that moment on—it does not belong to them.” 03.07.22_anon

In line with supporting the notion of donation and emphasizing the sharing of personal data, one interviewee who is a researcher and serves on an advisory committee of a local biobank was fiercely against the idea of private ownership of DNA, defining its donation as an act of solidarity:

> “The donors who donate DNA actually do not donate something of their own. They are carriers of something that belongs to humankind. So they can be paid for their time or the inconvenience. But paying them for the DNA itself—this is returning to the collective.” 02.05.22_anon

Along with a broad agreement that a direct return to specific donors was impractical or not warranted, some, like the following bioethicist, agreed on a general return to the group of donors or to the public to which the donors belong, i.e., to the collective:

> “It isn’t at the individual level. It is at the collective level. It isn’t because I donated that I get prioritized. I get prioritized because I’m a part of the Israeli collective that decided and gave the samples.” 08.03.22_anon

The question of how and which benefits should be shared within a wider solidarity framework is controversial. There is only agreement on the implausibility of direct personal benefits, besides some minor compensation for time and inconvenience. Additionally, the interviewees agree that there should be some collective benefit to the population for the establishment of a national biobank. How exactly this benefit-sharing should proceed, remains unclear. In our discussion, we will try to address these conflicts.

The risks of excessive promises in a profit-driven economy

One of the sources of the previously mentioned conflict between ideas of solidarity when establishing a national biobank stem from the profit-driven nature of the economies, HMOs have to operate in. The business model of certain biobanks, addressed before as posing a challenge for their operation, was independently and separately addressed by one expert—a researcher serving on a local biobank's advisory committee who regarded it critically as a conflict of interests. This minority voice claimed that institutional biobanks belonging to HMOs—unlike a national biobank—operate in a problematic manner and breach their commitments to the donors, who donate to advance science. This could be seen as tension between open and publicly available data on one end and closed data, which is associated with costs for accessing, on the other. The critique on the latter claimed that the public is lured to believe that donating promotes research. However, the HMO, as the operator of the biobank, limits the access of potential research bodies out of illegitimate profit- driven motives:

> "They guard their own interests, they look for their financial profits, and this thing harms the availability of research. They deceive the donors if they tell them "I'm doing it for the sake of science" and in fact they turn it into an income source." 02.05.22_anon

Another relevant problematic aspect mentioned by some respondents regarding biobanks belonging to HMOs is derived from their double hatting: They are organizations providing health services who collect data on patients while doing so AND they trade in the very data they collect.

We asked about views concerning the profits made by commercial firms (not by HMO's) which gain access to the biobanks and develop medical products based on their data. It was apparent that the respondents found it acceptable or unavoidable. Interviewees did not associate any feelings of unfairness or exploitation to such profits. Many respondents, as the following interviewee from the ministry of health, explained that this was the only mechanism to ensure the conduction of research to promote medical developments for the common good, thereby reaffirming the existing socioeconomic political structure without challenging the logic of the market:

> "I think there are firms that earn a great deal of money. These are the pharma and diagnostic firms and those that develop the products. […] It is all a matter of trade-offs, and the *alternative* would have been that this cure would not have been developed and perhaps people like you and me would not have had medicines." 03.07.22 _anon

The lack of a mechanism for the management of the economic aspects is emphasized by some of the more critical respondents in light of this unclarity. Indeed, some respondents from various categories pointed out that a transparent mechanism for the regulation and management of public benefits is much needed, as this quote is an example of: *"The money earned from this must be transparent."*

(09.05.22_anon). This same respondent urged the creation of a “committee” that distributes the profits in such sectors as “education” and “culture” mirroring practices such as the Norwegian Pension Funds, famously reinvesting the country’s high revenue from the extraction of fossil fuels. Another respondent echoes those desires, underlying them with concerns about the inefficacy of Israel’s healthcare system:

> “It [the earnings] should not reach the HMOs because it will disappear and have no effect. [...] There should be an appointed fund that promotes research and development in the medical arena and the state will decide every year where to invest the earnings.” 03.07.22_anon

Some, like the following respondent who is a medical doctor and entrepreneur, connected the call for a transparent mechanism to a general distrust in the authorities. The substantial delays in establishing the initiative and the associated failure to fulfill the promise of tremendous economic gains were blamed on the untrustworthy behavior of official bodies:

> “We are a nation of charlatans, and we do whatever we want. [...] I would not give my DNA to a system that has no transparency, and in which I have no trust.” 11.10.22_anon

The same interviewee was also suspicious regarding a question we could not answer: Was money already invested, how much, and where did it go? This critical interviewee pointed out the chasm between the bioethical discussion regarding biobanks and the discussion on the management of their financial benefits, suggesting that bioethics (in the form of what is practically a blanket consent) is used to hide biopolitical and financial aspects. This interviewee, in consequence, calls for comprehensive transparency in all the decision making process.’

Others, however, as this interviewee with a management position in a local biobank, maintained trust in the fairness of state institutions, even when recognizing the instability that characterizes the Israeli regime and the associated unclarity regarding budgets and ever-changing priorities:

> “The health basket in Israel is very wide and I would like to believe that I can trust the health basket committee to include [appropriate services]. Of course, at the end of the day it is all based on economic considerations.” anon_16.02.23

Despite this trust in the Israeli healthcare system, its different components such as HMO’s and hospitals were competing with each other in a manner that delayed the establishment of Psifas. This non-solidaristic conduct, emanating mainly from financial contests undermines the myth of the Israeli health system’s socialist-solidaristic roots, and disagrees with its naïve trust. This rift between public expectation and operational reality creates a dangerous climate that could contribute to a breaking down of the solidarity principle, therefore endangering societal reproduction. We will discuss this further in the next section.

Discussion and conclusion

Even though the Israeli national genomic biobank initiative was presented by the Israeli authorities as one of significant economic value, our findings show that the financial aspects were not made transparent, even for the professionals whose expertise is related to biobanking. We looked for, yet could not find, clear and measurable criteria for evaluating, let alone sharing, the financial gains from the initiative with the wider public. Indeed, there was no consensus among the professionals as to the expected profits, the beneficiaries, and the desired distribution of direct financial gains.

The sole reference to monetary benefits clarifies that should the associated research yield any—those will be owned by the researchers, whereas the donors will not enjoy these fruits. This is in line with the work of Samuel et al (2022), which shows that biobanks are framing their purpose only in medical and promotion of healthcare terms. Consequently, the authors call for clear explanations to be provided by biobanks regarding the nature of their public/private interactions, their associated benefits and risks and their distribution to the public.

Since the DHI has not fully materialized and Psifas biobank was only recently launched, taking its first steps, we could not check how the economic aspects of the project were communicated over time to the public and more specifically—to donors. The two former main Israeli biobanks (Midgam and Maccabi's "Drop for Research"), emphasize in their PR documents their contribution to the advancement of healthcare for the common good, while economic incentives, goals or benefits to the wider public are not deliberated or communicated (Raz and Hashiloni-Dolev 2022). The only mention of economic aspects relating to the donors is the one in which the donors renounce any compensation for their participation or any claim for profits originating from research based on the biobank. In the same manner—and despite the government's official announcement about the initiative's substantial national economic value—Psifas's website in its call for potential donors mentions only medical motivations and refrains from mentioning economic aspects.

Furthermore, our findings show that even though there is broad agreement among the respondents as to the resulting benefits to healthcare for the wider public, there is no parallel clear understanding of the economic value of biobanks on a national level or for the donors themselves. Most respondents framed this topic as part of future promises clouded by a rhetoric of the public good. This blind spot demonstrates the lack of expert as well as public discussion of what actually consists in 'the public good' beyond the bland statement that individual donors would be acting responsibly by participating in research. This is most striking in the context of the health system in Israel that, although running a series of public-private collaborations, is still a public enterprise. Our analysis, though, suggests that professionals active in the field of biobanks cannot imagine a different world based on different values. They, still, all see the rules of the market as the only available or realistic option for promoting health. They do not even bargain about how profits should be divided. They take it for granted that the pharmaceutical industry and its economic logic is the only way to move forward with data collected and generated by biobanks. Other forms of public benefits are hardly discussed. A frame of mind in which innovation is inclusive and rewards are shared seems beyond their imagination. Public benefit is black-boxed as research for the benefit of society without delving into what and how specific research can benefit society and the wider public.

The research of pharmaceutical companies just trickles down to somehow ameliorate people's health. Experts seem to believe that each individual "drop" of DNA for research will add and culminate in a large-scale reservoir for research that will become a pool of biomedical progress. This progress will in turn permeate back to the public, somehow. However, the case is more often when mechanisms are not established, that it is the strong who reap all the benefits, whether in economical or medical aspects. The main economic benefit for the wider public that respondents could agree on is the creation of some high-value jobs in the pharmaceutical sector. These jobs provide a high income and in turn boost the economic situation for others as those people will invest back in the economy through spending. In turn, this spending creates more jobs and, thus, more economic value for everybody. Therefore, the overall economic benefits rest on the idea of the trickle-down effect, a most controversial concept that has been questioned for decades (e.g., Arndt 1983; Akinci 2018).

It is not a coincidence that such large-scale genomic repositories are called bio*banks*. The bank serves as a financial market that ideally benefits both the depositors and the debtors, yet in practice, all profits go to high-value customers because they hold large deposits or have outstanding loans. The individual, and the public, do not stand to gain from the banking industry, unless we actively promote an alternative worldview that takes seriously the DNA donation of individuals (Prainsack and Buyx 2013).

Indeed, large-scale genomic research in biobanks has already been a catalyst of reshaping the power relationship between the Establishment and indigenous, ethnic, and religious communities (Claw et al 2018). Concerns about the misuse of DNA have caused marginalized communities to refrain from participating in genetic studies. Without these communities participating, biobanks will not provide the promised diverse genomic picture of the whole population. Increasingly, more individuals ask what they can get from participating, and some communities demand benefits for sharing their members' DNA (Guglielmi 2019; Claw et al 2018). With new technological advancements, increased awareness of past transgressions, and a recognition that extractive research causes harm in a variety of ways, we hope that communication efforts can increasingly focus on genuine engagement on genomic research, especially when it comes to under-represented populations (Raz et al. 2022). Future endeavors will need to address solidarity in a holistic way, making explicit how to implement mechanisms safeguarding equitable benefit—sharing with the wider public. The notion of solidarity (genomic and social) has increasingly become a red flag to such individuals and communities, indicating the creation of a situation of Parasitical Solidarity (Weiss 2025; Shults 2024). As their solidaristic motivation has been misappropriated in the past, these marginalized groups become suspicious of the authenticity of overarching promises. Solidarity loses its normative appeal and turns into a warning indicator. As solidarity represents an etiological function of (democratic) societies (Bureli and Camboni 2023), this development represents a huge red flag, endangering societal cohesion. As our interviews showed, such a situation where solidaristic intentions get misappropriated seems already in the making. Experts complained about an obscure overuse of solidaristic rhetoric while simultaneously biobanks artificially limit access to their data out of profit-driven motives. On the one hand, solidaristic practices cannot and should not be directly compensated, and thus, turning into a contractual arrangement. On the other hand, there should be some possibility of a future benefit for people like yourself (Prainsack and Buyx 2017), whether through overall improved health services or more specific advancements such as customized treatments for marginalized groups. According to our interviews, there seems to be a disconnection between the actual donors and the short-term benefits for them and the wider public, especially economic benefits, they can expect. As the interviewed experts agreed more on the medical benefits for the wider public, there seems to be a better case for the solidaristic framing from a health perspective. Rather than dismissing the option of solidarity, we need to create transparent mechanisms of benefit-sharing—medical, financial and economic. The Israeli institutional infrastructure operated by public agencies rather than private organizations, renders it as an ideal candidate for establishing solidaristic practices.

We thus fully agree with Prainsack and Buyx' (2017) for the need to reframe the relationship between participants and biobanks as informed by both solidarity and autonomy. These authors have proposed that, instead of a dominant or exclusive focus on protecting autonomy of the participant, a shift is needed toward more harm mitigation; a commitment to veracity; the use of trusted intermediaries; and data sharing. Therefore, the framework of "data solidarity" (Prainsack et al 2022a; 2022b) should be applied. This framework classifies biobanks as Type A or Type B data use, depending on the assessment of the public value this data use could facilitate. As our expert interviews have shown, there is wide agreement, that biobanks will facilitate important discoveries. Thus, it seems as if biobanks would rather be classified as Type A data use[10]. In the realm of medical benefits, a data-solidaristic framework is one that incentivizes or even prescribes certain use of the data and the profit generated from this data use and the knowledge creation it facilitates. As the Israeli biobank is not a private company, but rather a public enterprise interacting with profit-oriented actors, it is an ideal playground for establishing data-solidaristic practices. Policymakers could for instance prescribe that a certain amount of financial profits have to be invested in the research of so-called orphan diseases. Another possibility would be to tax direct profits derived from data use by pharmaceutical companies and invest those funds in a public research fund. Consequently, this data use should be encouraged as long as harm mitigation is in place.

Examples of benefit-sharing in biobanks also include establishing dedicated funds for compensation of low-income affected donors, and regulations requiring

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[10] This is our medically untrained, social scientist assessment after studying the topic by interviewing experts in the field and presenting the findings in this paper. Such assessments should be continuously reviewed and adjusted accordingly.

pharma companies that gain profits from biobank research to earmark a percentage of the profits for the public good such as the aforementioned subsidizing of rare diseases research, or treatments targeting low-income under-developed marginalized communities that donated to the biobank. To avoid Parasitical Solidarity (Weiss 2025; Shults 2024), therefore, respecting the epistemic requirements of solidarity (Pongiglione 2024) and striving for inclusive innovation, the establishment of a national biobank should be accompanied by the establishment of clear guidelines for what kind of research the data and how the respective results should be used. While the Israeli health system is divided into competing HMOs in a way that fosters fragmentation, a truly "national" and "public" biobank should strive to balance such fragmentation. Provisions, such as incentives to research orphan diseases or regulations of the costs of newly developed treatments offered to the HMO, could fulfill this role. Instead, the responsible actors seem to be satisfied by a vague prospect of medical progress trickling down to patients in need as well as direct profits somehow trickling down to the national economy. Such indifference to the actual beneficiaries reinforces the impression of our previous study that it is not an endeavor to create a real "public" biobank, but rather a stunt to shroud a "population- based" biobank (Raz and Hashiloni-Dolev 2022). The solidarity rhetoric used in the establishment and the sensitivity of the matter stand in utter opposition to such a PR- stunt by the responsible political actors. Given the relevant novelty of the field, there are yet no social conventions and no market norms to organize the production, commercialization and profits of digital health and its potential usages (Fisher and Rosenhak 2022). We, thus, call for their establishment and propose data solidarity (Prainsack et al 2022a, b) as a potential framework that already addresses all of those questions.

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