BIO-BABBLE



Newsletter of the Australasian Biospecimen Network Association

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IT'S THE FINAL COUNTDOWN!

With all the musical references flying around in our 2023 program it seemed fitting to throw in another one! In under 3 weeks we'll be on the sunny Gold Coast for ABNA's 20th Anniversary Meeting "Biobanking On Record" and we couldn't be more excited. The final program is now available on our website and there's just over 2 weeks left to register. Accommodation at the Sea World Park is in incredibly short supply with all rooms now made available to the general public. With limited choices in the surrounding area, we suggest you get in quickly. We also have limited seats left for the conference dinner so if you'd like to secure one – now's the time!

To say that things have been busy at ABNA HQ over the last month is a massive understatement and we're delighted that we will soon be able to announce the outcomes of three new ABNA initiatives!

ABNA SPECIAL INTEREST GROUPS

Following the recent call for expressions of interest ABNA is now in it's final stages of confirming the successful proposals for Special Interest Groups. The received submissions were of an incredibly high caliber and we look forward to notifying the successful groups in the coming days before announcements are made at the annual meeting.

ABNA EMERGING LEADER SCHOLARSHIP

The ABNA Emerging Leader Scholarship, which closed to applications on Monday 25 September, is being launched to provide support to a newly emerging leader in biobanking or a leader who is making an impact in a novel or emerging biobanking discipline. This award is in keeping with ABNA's commitment to supporting early career biobankers and to encouraging diversity within the biobanking and biospecimen science discipline. The received applications are currently under review by ABNA and external reviewers and the successful applicant/s will be notified in the coming days.

2023 ACHIEVEMENT IN AUSTRALASIAN BIOBANKING AWARD

The ABNA management committee would like to sincerely thank all who submitted nominations for their biobanking colleagues. This award is designed for current ABNA members to recognise another member, past or present, who has contributed and/or continues to contribute to the Australasian biobanking community and upholds the ABNA core aims and mission. The inaugural award will be presented at ABNAs 20th Annual Conference Dinner.



5 MIN WITH A BIOBANKER

We approach a different professional in the biobanking arena with the same five questions each month.

This month we speak with Dr Mike Sheldon, Senior Director Scientific Affairs, SAMPLED https://sampled.com/



THE QUICK QUESTIONS

Red or white wine?

Neither, cocktail menu please. An Islay single malt is at the top of the list (I won't tell you which one)

Mac or PC?

PC

Batman or Superman?

Batman

(Doctor Who is better than both of them)

Lord of the Rings or Harry Potter?

LOTR

(Some days I'm a wizard, most days I'm an orc)

- 1. How long have you been working in biobanking?
 17 years
- 2. Which advance in science/research do you think has had the most impact on you as a biobanker?

Laboratory automation

- 3. In retrospect, given the experience you have now, what one piece of advice would you give to yourself at the start of your biobanking career?
 - Keep on the lookout for novel ways to combine different seemingly unrelated technologies and approaches
- 4. What is the craziest thing you have done to save a sample/s?

 Pick it up in the middle of a crowded road and run across with it!
- 5. Your career on record: name 3 songs/albums that best tell the story of your biobanking career:
- Reelin in the years
- She Blinded Me with Science
- Everybody Wants to Rule the World



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THE UNTAPPED POTENTIAL OF BLOCKCHAIN IN BIOBANKING

By Caspar Barnes

INTRO

There is a good chance that you have heard the hallowed word "blockchain" before, so I can only imagine your confusion when reading it in the same sentence as the word "biobanking". Perhaps your mind goes straight to Bitcoin and cryptocurrencies, or perhaps you've been accustomed with the basics of NFT's. Whatever your familiarity with the taboo technology, lend me 10 minutes of your time I'll do my best to persuade you that the blockchain-biobanking intersection is at least worth exploring further, and at best a panacea to all biobanking fallacies.





BLOCKCHAIN 101

So what even is a blockchain? Is it a cloud? Is it a server? A computer? Let's not make it excessively complicated; as scientists, all you need to know is that blockchain technology uses complex maths and cryptography (known as "protocols") to power web-applications that allow direct communication and transactions between users. Take banking for example; if you want to send \$10 to a colleague, you need a bank or automated clearing house to mediate the transaction. On blockchain powered platforms, the protocol acts as the intermediary, or better yet, the protocol allows you to not need an intermediary at all; you can simply send \$10 to your colleague for zero fees, and with zero liability or risk. Protocols also provide a way for you to turn unique real-world items into digital assets, which can be used to denote ownership, rights, custody, or provenance of an item. Art is a great example, as a digital asset that represents a unique art piece could ensure that the creator is always paid a royalty for its sale, or perhaps that the piece is only ever stored in a museum. The idea is that it comes down to trust: blockchain protocols remove the need for human intermediaries and allow web-based interactions to be trustful or trustworthy.

If protocols provide the trust, then smart contracts provide all the rest. Smart contracts are extremely customisable types of code that can be used to manage and power a great variety of blockchain based applications. Let's say James and I enter and agreement that if Australia win the rugby world cup, I'll pay him \$20, and if South Africa win, he'll pay me \$20. Instead of going to the bookies to place our bet, we'll bet directly with each other via a blockchain powered platform. We'll write a smart contract outlining our bet and both place \$20 into it, and the winner gets the cash; no way to back track or get around it. This is a simple example, but the underlying notion is incredibly powerful; imagine a world where you can directly agree, interact, promise, and exchange on nearly anything in nearly any industry, without the need for an intermediary or fiduciary. How might such a power be able to affect our world of biobanking?

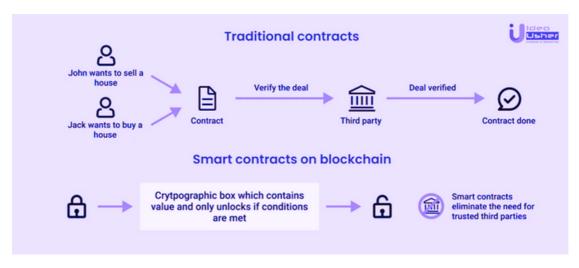


Image 1 - Illustration of Blockchain and Smart Contracts (Banerjee, 2021)

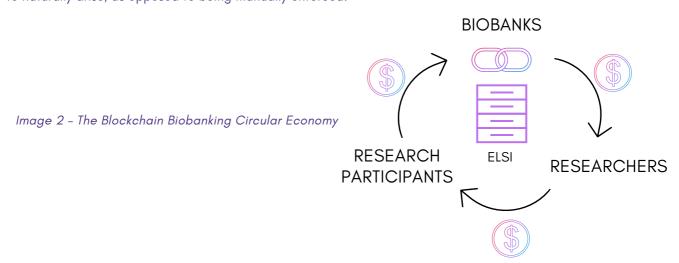
ELSI PRINCIPLES AND CONSENT IN BIOBANKING

Biobanks have grown an immense popularity over the last 30 years as they have become the backbone of powering precision medicine research (Annaratone et al, 2021). With this growth, an accompanying emphasis on Ethical (E) Legal (L) Social (S) Implications (I) has held steadfast the debate of what fiduciary roles biobanks have to both their research participants and bio-sample procurement entities (Kishimoto,2020). An abundance of biosamples and research data is only as good as the structured and considerate mechanisms in which we return the scientific and commercial value, as after all, without patient consent everything down stream is futile. Some fields of biobanking today run the risk of turning informed consent documents into a waiver of liability for the researcher as opposed to a framework for including the donor in the research process, and blockchain technology presents itself as unique opportunity to keep incentives and output aligned between research participants, research entities, and biobanks themselves.

ELSI/ELSA

The acronyms ELSI (in the United States) and ELSA (in Europe) refer to research activities that anticipate and address ethical, legal and social implications (ELSI) or aspects (ELSA) of emerging sciences, notably genomics and nanotechnology. ELSI was conceived in 1988 when James Watson, at the press conference announcing his appointment as director of the Human Genome Project, suddenly and somewhat unexpectedly declared that the ethical and social implications of genomics warranted a special effort. Subsequently, ELSI was first formally recognised in 1990 during the initial assessment of the Human Genome Project.

Bio-samples harbour an inherent uniqueness in that they fasten the entire health identity of an individual; they have a distinct provenance, a distributed ownership, and are non-fungible. This is what makes them perfect illustrations of real-world objects that would tremendously benefit from a digital asset representation. A blockchain biobanking ecosystem in which all donated material were turned to digital assets, would allow donors, researchers, and biobanks to equally share in who owns the sample, who has rights to its associated and generated data, and how this information defines unmet medical need. In the current instances where consent documents are seen as a "tick box" exercise, and in other instances where samples are limited by informed consent such that they are used once and subsequently hoarded forever, blockchain biobanking would allow the donor to give personalised consent for broad use of their sample. All biobanks and researchers would be able to search the inventories of available samples in the peer-to-peer network, and the donors' permissions would be the defining factor as to whether the sample is shared or not. The monetary exchange for acquiring the samples would subsequently trigger automatic royalty payments to all those involved, ensuring that the financial incentives align to create a circular biobanking economy. This self-sustaining biobanking model would allow ELSI principles to naturally arise, as opposed to being manually enforced.



CASE STUDY - Malta Biobank & Dwarna

The Maltese population has a unique genetic architecture, reflecting its shared genetic ancestry with European and Middle Eastern populations. Against this background is the first study to draw on a nationally representative cohort of biobanked samples and data, obtained from DwarnaBio, the Maltese national biobank led by the University of Malta. DwarnaBio will be a powerful tool that facilitates prospective cohort studies, biomarker research as well in-depth genetic epidemiological studies.

The Dwarna portal for dynamic consent which harnesses the blockchain model, will act as a hub connecting the biobank managers, researchers, research partners (participants), and the general public. Research partners log onto the Dwarna portal using their pseudonym and a password to learn about ongoing research, indicate their consent to join a particular study, withdraw consent or demand the erasure of their data and the destruction of their biospecimen from the biobank. DwarnaBio seeks to primarily prioritise direct public engagement in research. It represents a move away from the traditional concept of research subjects as passive sample donors to emphasising a proactive and collaborative approach that considers the general public as an active research participant.

THE BIG PICTURE

Biobanking will undoubtedly continue its exponential growth into the 21st century, however a business-as-usual scenario would let mistrust, scepticism, and apprehension continue to gnaw at the lifeline of our industry (i.e., donor consent). We all know that we need to find alternative ways to build trust in the ecosystem (Parikh, 2021), but in my mind, trust can never be built by inundating donors with information on a consent document and occasionally updating participants on the status of a couple studies. The simple equation for trust is engagement plus accountability, over time; we need to allow donor communities to be a part of the discourse around the rights, ownership, and economics of biobanking, and we need to do so consistently. Transparency and benefit-sharing needs to be embedded into the very fabric of the biobanking industry, and blockchain presents itself as the perfect tool to leverage to this affect.

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If you have any suggestions for a short article for Bio-Babble, please contact: abna.biobabble@gmail.com

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