

The Bio-PIN

for privacy protection in medical research

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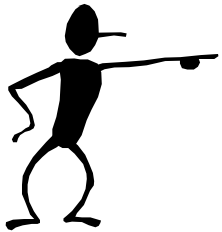


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INTRESCO

If patient data and samples would be anonymously collected in a Biobank for medical research



- Privacy would be maximally protected, better than under the GDPR!
 - Differences in privacy laws not relevant.
 - No errors in names and birth dates.
 - GDPR does not apply to anonymous data.
- Anonymity would have disadvantages:
No contact between Biobank and patient!

Solution?

- Can one set up anonymous Biobanks without this disadvantage?

Yes!

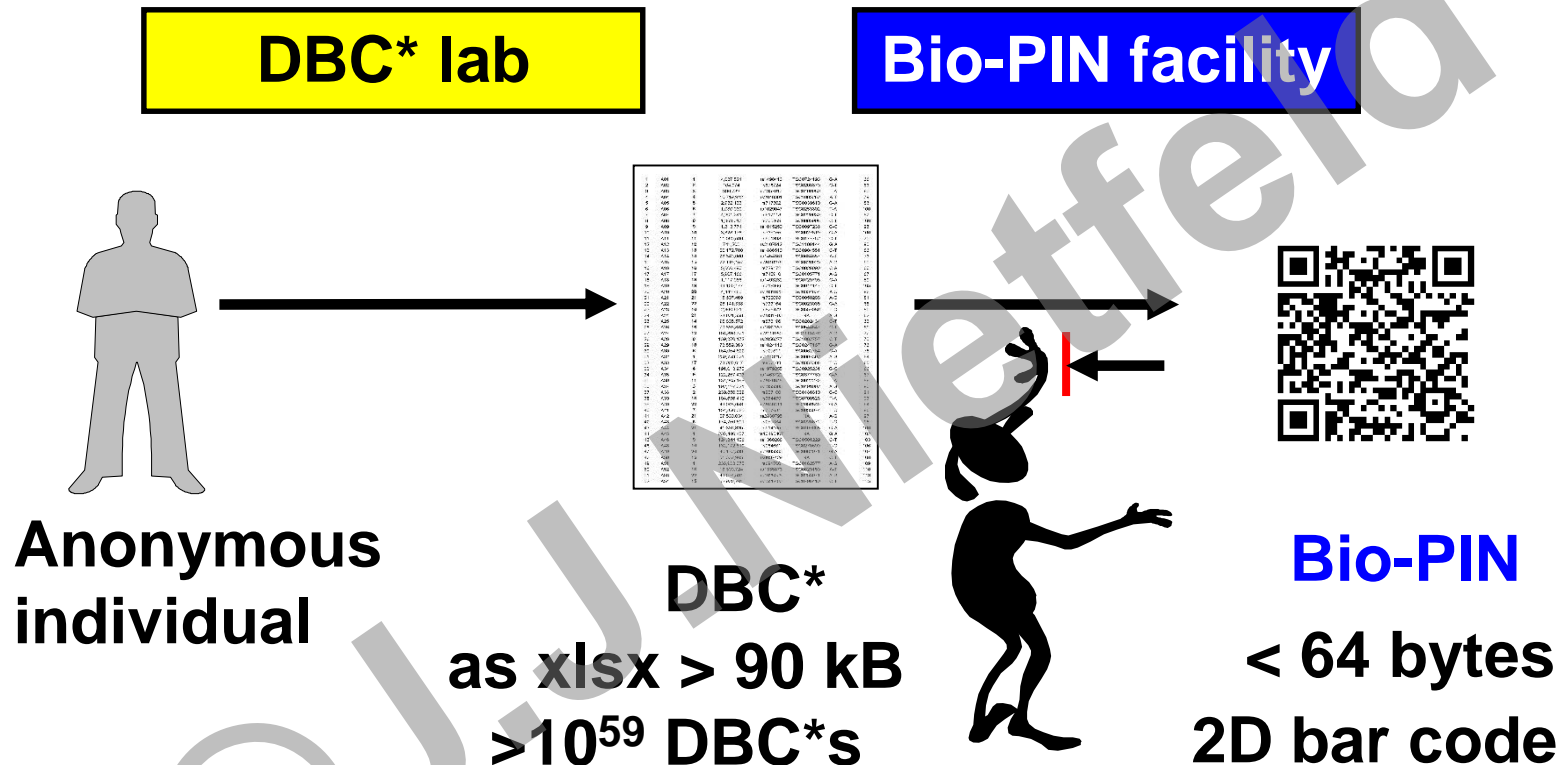
- Replace identity data with the **Bio-PIN**.
 - Data & samples become anonymous.
 - Bi-directional communication possible.
- ◆ A person's name has no biomedical meaning, in medical research it is not needed.



What is the Bio-PIN?

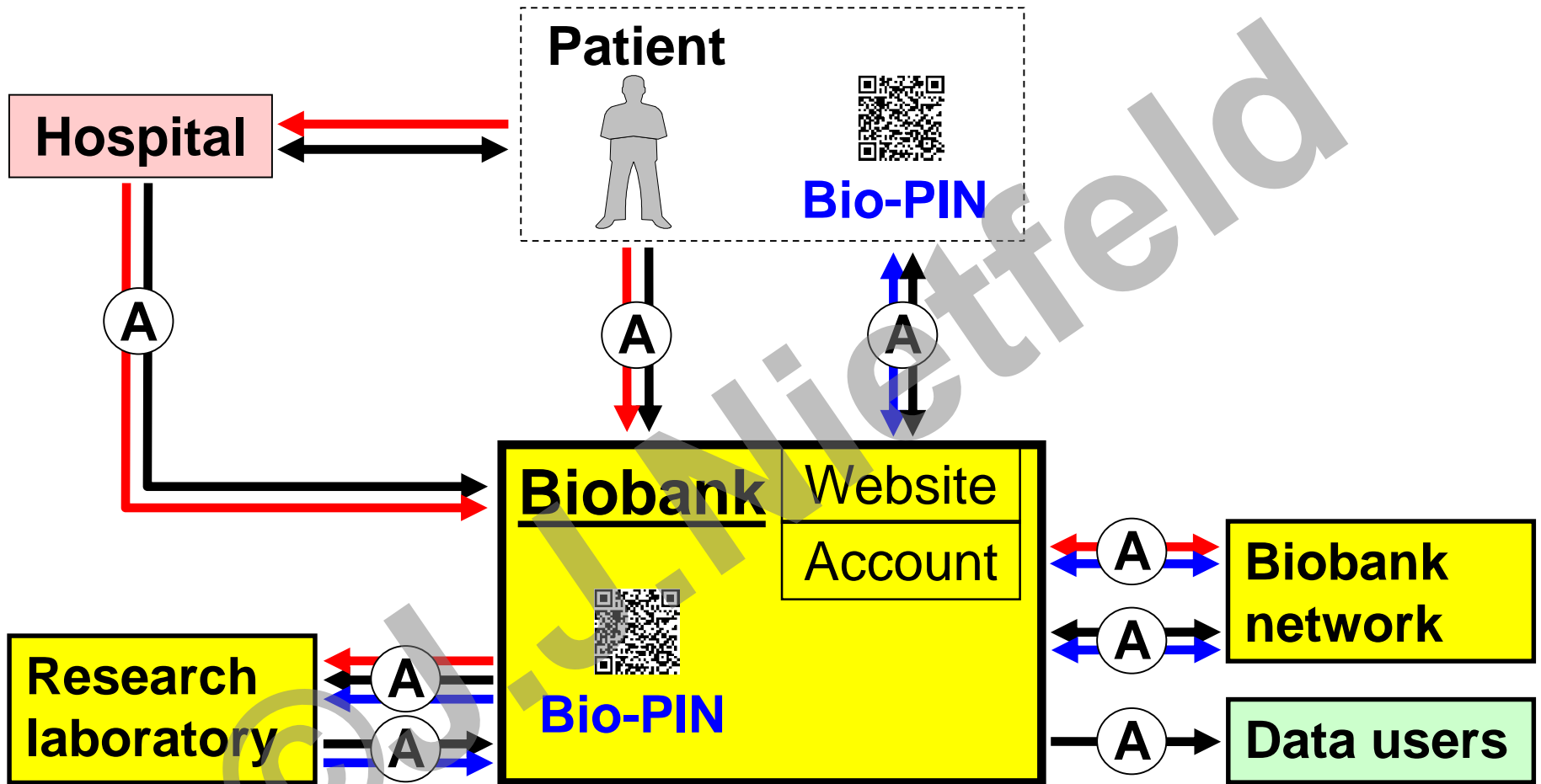
- A biological PIN code based on a Distinguishing Biological Characteristic (DBC) of an individual.
DBC: Biochemical parameters + birth order number.
 - No phenotypic data (e.g. hair/skin/eye color).
 - No diagnostic or prognostic medical data.
 - No gene data.
- Unique for any person (also identical twins/ multiples).
- Anonymous (if based on an anonymous DBC).
- Cannot be linked back to the DBC.
- The **Bio-PIN** does not constitute personal data.

Bio-PIN production



* = Distinguishing Biological Characteristic, < 10⁻¹⁸

Bio-PIN use



Ⓐ = Anonymous → = Material → = Data → = Bio-PIN

Bio-PIN advantages for patients

- + Maximum privacy protection (better than the GDPR)
- + All rights intact.
- + Bi-directional anonymous communication.
- + Safety (unalienable) & Sustainability (once).
- + If lost, the same Bio-PIN can be reproduced.
- + If compromised, a new Bio-PIN can be produced.
- + Personal Electronic Health Record possible.
- + Strengthened autonomy.

Advantages for Biobanks/ researchers

- + Maximum privacy protection (privacy by design).
- + Linking of data/ samples in different Biobanks.
- + Bi-directional anonymous communication.
- + Errors in identity data not an issue.
- + If lost, the same **Bio-PIN** can be reproduced.
- + If compromised, a new **Bio-PIN** can be produced.
- + Less impediments for (international) research.
- + Savings in work, time and money.

Conclusions

- The **Bio-PIN** can create a win-win situation:
 - Maximum privacy protection for patients.
 - No GDPR impediments for Biobanks/ researchers.
 - The **Bio-PIN** can lead to a whole new ethical, legal and societal framework for use of patient data/ samples in medical research.
 - The **Bio-PIN** is superior to other systems (cf. random numbers/ other irreproducible markers).
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- **Bio-PIN** concept in *Nature & Nature Reviews Cancer*.
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