

# Athlete Biological Passport: ethical challenges

@PascalBorry 

Professor Pascal Borry

Centre for Biomedical Ethics and Law, Department of Public Health and Primary Care, University of Leuven

# Overview

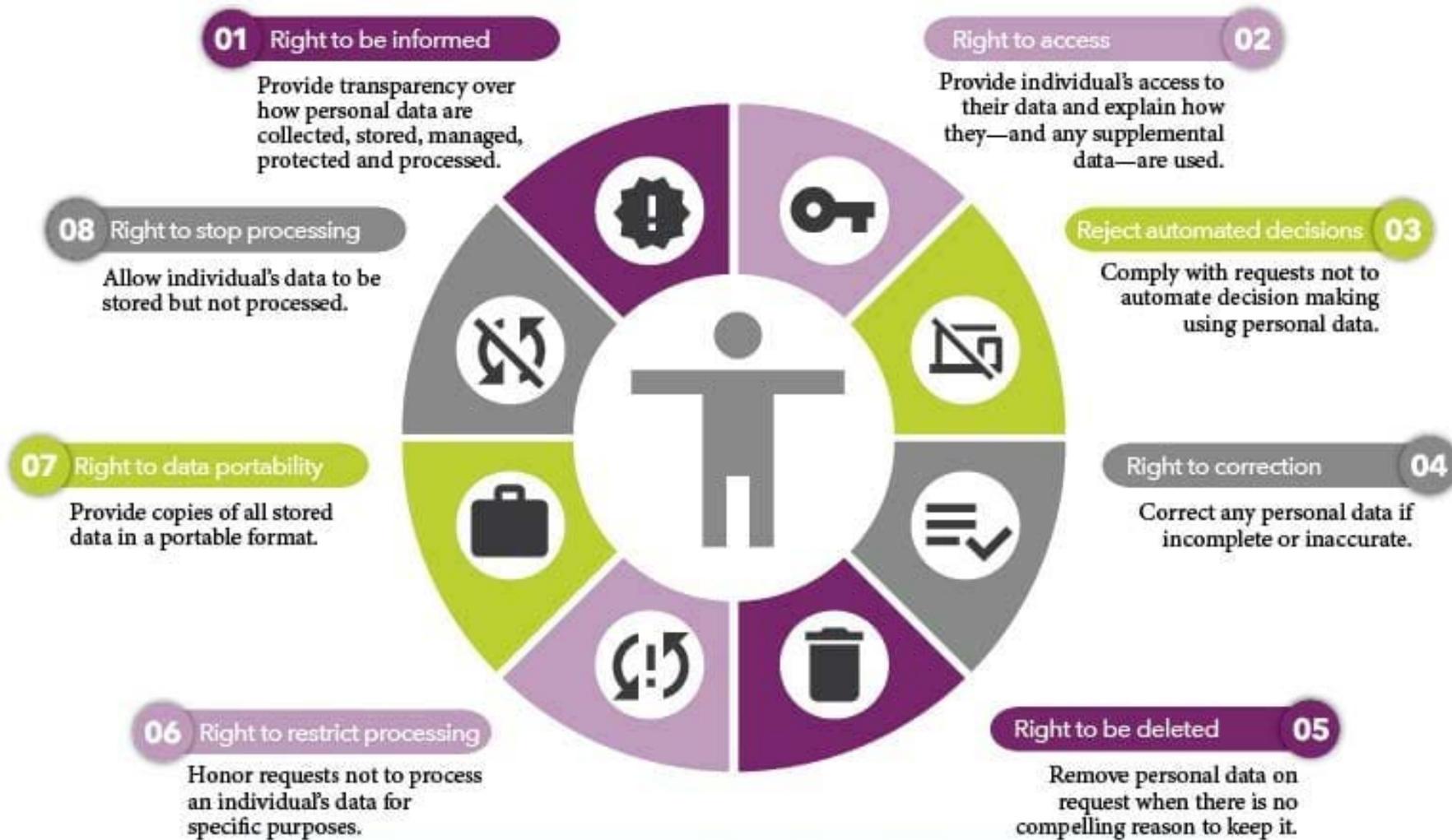
- Athletes' access to ABP data
- Incidental findings
- ABP+

# Athletes' access to ABP data





# 8 INDIVIDUAL RIGHTS



The GDPR contains 56,321 words in 99 articles spanning 261 pages. DLP has certified Data Protection Officers on staff to help navigate the statutes and bring your business into compliance before May 25.



# ABP data: personal data

- “‘personal data’ means any information relating to an **identified or identifiable** natural person (‘data subject’); an identifiable natural person is one who can be identified, **directly or indirectly**”
- “the right to obtain from the controller confirmation as to whether or not personal data concerning him or her are being processed, and, where that is the case, **access to the personal data**”

# ABP data: derogations on personal rights

- Restriction respects the essence of the fundamental rights and freedoms and is a **necessary and proportionate measure** in a democratic society to safeguard:
- (a) national security; (b) defence; (c) public security;
- (d) **the prevention, investigation, detection or prosecution of criminal offences** or the execution of criminal penalties, including the safeguarding against and the prevention of threats to public security;
- (e) other **important objectives of general public interest** (...) including monetary, budgetary and taxation matters, **public health** and social security;
- (f) the protection of judicial independence **and judicial proceedings**; (...)
- (i) the protection of the data subject or the rights and freedoms of others;
- (j) the enforcement of civil law claims.

# ABP data: derogations on personal rights

- ABP data disclosure could permit athletes to improve doping techniques and calendar
- Data disclosure could, then, compromise fairness and integrity of sport
- Criminal charges

# ATHLETES CAN BE CLEAR WINNERS BY PUBLISHING DATA

The Olympic silver medallist *Roger Black* believes athletes publishing their data would “act as a deterrent” to cheats as he calls for more transparency within the sport.

What this investigation has

For athletics to move forward  
watch a race, see incredible



te years  
se people  
anson i  
stions r  
onvince  
honest  
ciple, I

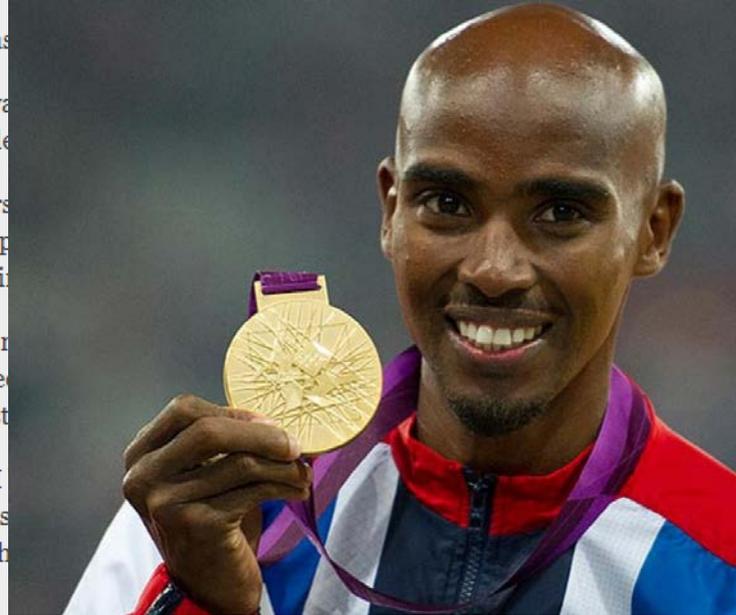
I was s  
public domain?”, I would h  
nothing to hide.

Cheating is a mindset and once you cross that line you can never come back. Everyone knows where that line is. Everyone knows what they can and can't do as an athlete. It's all about

**Mo Farah publishes blood test data to show he is within normal range despite being warned not to by authorities**

I too  
such  
how  
publishing more data would be an effective tool.

If you are going to assume that, on the whole, an athlete has nothing to hide, then why shouldn't they get their data out there? It could also act as a deterrent. If an athlete knows they will have to publish their data then it would make them think twice about cheating.



because we all want races to be clean.

rtant thing: for people to be able to

dal so you must have taken drugs”. I  
cleanly. That I never cheated. That I  
e very best.



**I would have said,  
'Absolutely.  
Publish my data.'  
Because I had  
nothing to hide.**

# ABP data: access rights

*[3.2 Comment: It is understood that Personal Information includes, but is not limited to, information relating to an Athlete's name, date of birth, contact details and sporting affiliations, whereabouts, designated therapeutic use exemptions (if any), anti-doping test results, and results management (including disciplinary hearings, appeals and sanctions). Personal Information also includes personal details and contact information relating to other Persons, such as medical professionals and other Persons working with, treating or assisting an Athlete in the context of Anti-Doping Activities. Such information remains Personal Information and is regulated by this Standard for the entire duration of its Processing, irrespective of whether the relevant individual remains involved in organized sport.]*

WORLD ANTI-DOPING CODE  
INTERNATIONAL  
STANDARD



## PROTECTION OF PRIVACY AND PERSONAL INFORMATION

JUNE 2018

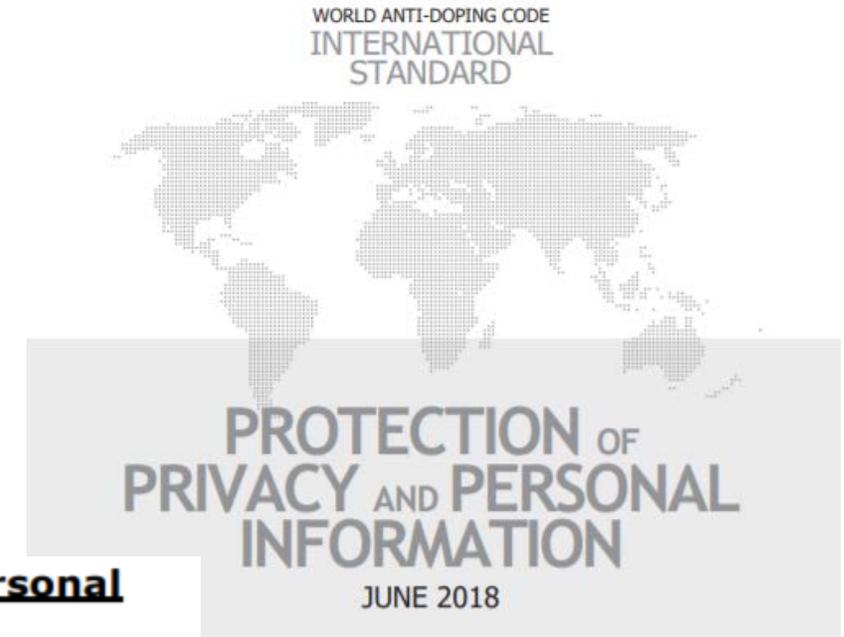


# ABP data: access rights

- Right to access:

## **11.0 Rights of *Participants* and Other *Persons* with Respect to Personal Information**

**11.1** *Participants* or *Persons* to whom the Personal Information relates shall have the right to obtain from *Anti-Doping Organizations*: (a) confirmation of whether or not *Anti-Doping Organizations* Process Personal Information relating to them, (b) the information as per Article 7.1, and (c) a copy of the relevant Personal Information within one month, where practicable, or as soon as possible thereafter, in a readily intelligible format, and without excessive cost, unless to do so in a particular case plainly conflicts with the *Anti-Doping Organization's* ability to plan or conduct *No Advance Notice Testing* or to investigate and establish anti-doping rule violations.



# ABP data: access rights

- “unless to do so in a particular case plainly conflicts with the Anti-Doping Organization’s ability to plan or conduct No Advance Notice Testing or to investigate and establish anti-doping rule violations.” (ISPPPI 11.1)
- Anti-Doping Organizations have to respond to requests, “except if doing so imposes a disproportionate burden on the Anti-Doping Organizations” (ISPPPI 11.2)
- Data disclosure policies might differ in practice: unequal treatment
- ADAMS: hematological data is accessible, not steroidal data at this moment

# ABP data: access rights

## Do athletes have a right to access data in their Athlete Biological Passport?

Thijs Devriendt  | Davit Chokoshvili | Maddalena Favaretto | Pascal Borry PhD

Department of Public Health and Primary Care, Centre for Biomedical Ethics and Law, University of Leuven, Belgium

Correspondence

Pascal Borry PhD, University of Leuven, Department of Public Health and Primary Care, Centre for Biomedical Ethics and Law, Kapucijnenvoer 35 blok d – box 7001, 3000 Leuven, Belgium.

Email: pascal.borry@kuleuven.be

### Abstract

The Athlete Biological Passport (ABP) refers to the collection of data related to an individual athlete. The ABP contains the Haematological Module and the Steroidal Module, which are used for the longitudinal monitoring of variables in blood and urine, respectively. Based on changes in these variables, a statistical model detects outliers which indicate doping use and guide further targeted testing of the athlete. Presently, athletes can access their data of the Haematological Module in the Anti-

# Searching for an alternative approach

- Not an official WADA position
- A possible solution is to set a **specific delay to disclose data** to the athlete that will harmonize data disclosure across ADOs
- Starting principle: **protection of the integrity of the system**
- **The results of each test can only be disclosed after the subsequent test has been performed or after a standard interval**
- Access rights doesn't mean automatic access

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- Incidental findings
- ABP+

# Incidental findings

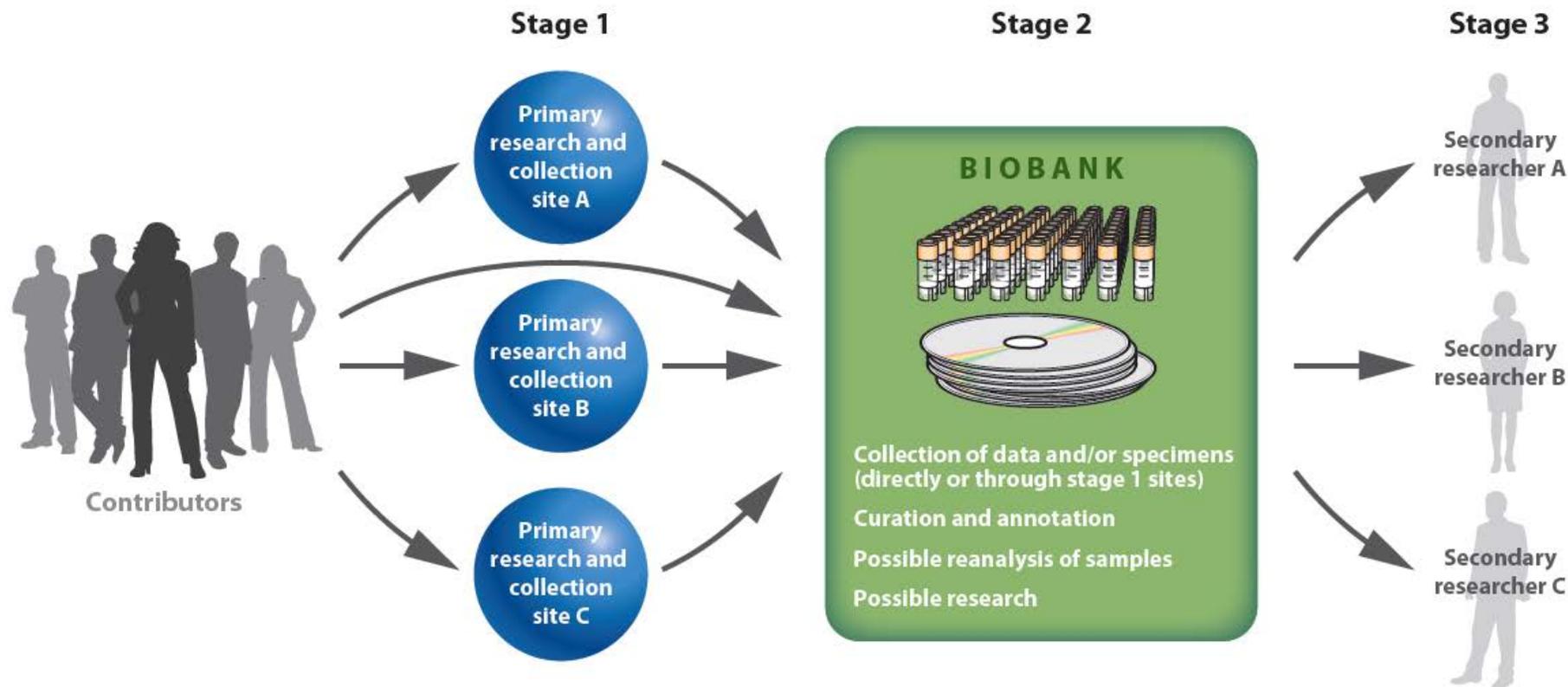
- Data in the ABP includes variables that are of a medical nature
- Medically relevant information:
  - Abnormalities possibly indicating undetected pathologies and thus being helpful for medical diagnosis and care
  - For example: risk of anemia (for adult men if HGB<130g/l); iron deficiency (MCV<80fL; RDW-SD>46fL, possibly lowered HGB) or polycythemia vera (for adult men: HGT>49%, HGB> 165g/L, red cell mass: 25% above mean normal predicted value)

# Incidental findings

- Relevant concepts in a medical context: duty of care; negligence
- Duty to rescue & Duty to warn:
  - “disclosure may be justified to protect individuals or society from **risks of serious harm**, such as from serious communicable diseases or serious crime.” (British Medical Association)

# Incidental findings

- Research



# Incidental findings

- Duties to anticipate and manage incidental findings in their research (in research protocol and informed consent)
- Criteria for return (Wolf 2008)
  - Should return: strong net benefit to the participant
    - “Important health implications, revealing established and substantial risk, when the findings were actionable (defined as having the potential to change the disease course.)”
  - May return: possibly net benefit to the participant
  - No return: unlikely net benefit

# Incidental findings

- Ethical dilemmas for ABP data handlers:
  - ABP is not intended as a health check or for medical monitoring (outside the scope)
  - Clinical interpretation not always straightforward
  - Not necessarily the right expertise
  - Incidental findings were not really anticipated in communication with athletes (e.g. no informed consent)
  - Potentially beneficial for athlete

# Incidental findings

## **WADA Technical Document – TD2019APMU**

Document Number:	TD2019APMU	Version Number:	1.0
Written by:	<b>WADA</b>	Approved by:	<b>WADA</b> Executive Committee
Date:	20 September 2018	Effective Date:	01 March 2019

### **Athlete Passport Management Unit** **Requirements and Procedures**

- “Likely medical condition” - the APMU shall update the APMU Report indicating “Likely medical condition” with submission to additional Experts if recommended in the Expert evaluation, and should inform the **Athlete** via the **ADO**.

# Incidental findings



## 2.2.2.1 Anti-Doping Organization

The **ADO** is responsible for:

- Adopting, implementing and administrating an **ABP** program in accordance with these Guidelines, including compliance with the **ISTI**.
- Establishing an internal or external **APMU** to manage the **ABP** program.
- Ensuring that recommendations received from the **APMU** are followed by effective, targeted, timely and appropriate **Testing**.
- Establishing, and implementing a test distribution plan, in consultation with the **APMU**.
- Sharing of relevant information with internal investigations personnel and other **ADOs** (when appropriate).
- When the **ADO** is the **Passport Custodian**, following up on **Adverse Passport Findings (APFs)** in accordance with **Code** and ISTI requirements.
- Informing the **Athlete** in case the **Passport** indicates a likely pathology as determined by the **Experts**.

ISTI, ISL

## ***Athlete Biological Passport Operating Guidelines***

Version 6.1

July 2018

# Incidental findings

- No duty to hunt for ‘incidental’ findings
- Need for better guidance: what to report, who should inform, when to inform, how to inform
- Not providing a diagnostic test, neither a diagnosis
- Relationship with law enforcement, public announcement and suspension

# Overview

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# ABP+

- OMICS: Genomics, transcriptomics, proteomics and metabolomics
- Gene expression profiles (e.g. to detect usage of small dosages of rHuEPO (Pitsladis et al. 2014))
- Variant in CYP17 gene: could lead to high T/E ratios in Steriodal Module
- Variant in UGT2B17 gene: could lead to lower T/E ratios
- Genotyping could help understand seemingly abnormal baselines values

# ABP+

- Analytical validity and clinical validity
- Clinical consequences? For athlete and relatives
- Informed consent (written in some countries)
- Medical prescription and genetic counselling (obligatory in some countries)
- Right not to know
- Stigmatization (cf. CYP17variant causing lower T/E values in Asian populations)

Downloaded from <http://bjsm.bmj.com/> on March 4, 2018 - Published by [group.bmj.com](http://group.bmj.com)

**BJSM Online First, published on March 2, 2018 as 10.1136/bjsports-2017-098299**

Consensus statement



**OPEN ACCESS**

## Geolocalisation of athletes for out-of-competition drug testing: ethical considerations. Position statement by the WADA Ethics Panel

Pascal Borry,<sup>1</sup> Timothy Caulfield,<sup>2</sup> Xavier Estivill,<sup>3</sup> Sigmund Loland,<sup>4</sup>  
Michael McNamee,<sup>5</sup> Bartha Maria Knoppers,<sup>6</sup> on behalf of the WADA Ethics Panel

# Advantages and Concerns

- Any GPS enabled device could be used to provide continuous information about location and whereabouts.
- Lesser risk of missing an out-of-competition test.
- Administrative burden is diminished.
- Could aid in the interpretation of ABP data is properly integrated e.g. altitude.
- Further infringement of privacy
- Doesn't remove the administrative burden
- Data security concerns related to continuous collection of data.
- Unreliable GPS systems (e.g. forests)
- Human error; forgetting, or breaking the device
- Purposely cheating; e.g. giving the device to someone else.

# ABP+

- The benefits remain largely hypothetical and minimal, while the potential invasion of privacy and the data security threats are real.
- Currently, it seems likely that the technology could result in more harm than benefit to athletes, the sport and the antidoping movement.
- Could be useful for understanding the association between genotype, phenotype and environment, in particular altitude.
- Conducted within a controlled research environment, with informed consent, and outside an antidoping context.

# Thanks!

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