**4. Finding the Balance: Individual Rights vs. Scientific Progress**

I think of presenting first 3 examples, one in which ethics were not respected in the study, one in which it was and one that falls in the middle. After that I’ll enter a bit into **Ethics-by-Design / Privacy-by-Design, Ensuring True Informed Consent .**

**Ethics-by-Design / Privacy-by-Design**

* Embed ethics into the development process (like security-by-design in software).
* Involve ethical experts **early** in research planning, not just at approval stage.
* Data Protection by Design and by Default

**Ensuring True Informed Consent**

* Not just a checkbox. Must be:
  + Understandable
  + Specific to purpose
  + Allow withdrawal at any time
* How manuacademic platforms fail this due to legal jargon or vague goals.
* Show contrast between Apple (clear, voluntary) and Facebook (hidden manipulation).

RealLife example:

**Gray — Emotional Contagion Study (2014)**

**Facebook conducted a study with Cornell University and University of California to see if manipulating users’ newsfeeds (positive or negative posts) could affect their emotions. It involved over 600,000 users, and no informed consent was taken.   
 The study resulted in some good insight, but Facebook being Facebook used users as lab rats.**

**Unethical — The STRAVA Heatmap Incident (2018)  
 Strava, a fitness company, released a public global heatmap of user workouts.**

**The data wasn’t really anonymized, and users didn’t consent to being part of a global data map.**

**The worst part is that soldiers used this app, and using the heatmaps, secret military bases were exposed. Also the results obtained by STRAVA were not relevant.**

**--------------------------------------------------------------------------------------------------------**

**With over 100 million users, Strava is one of the most popular fitness-tracking applications in the world.**

**One particular feature that Strava creates based on GPS data is the Strava heatmap. Updated monthly, the Strava heatmap takes the last two years of GPS data from participating users and aggregates it into a single map highlighting active areas with bright yellow and white lines. Participation in the Strava heatmap is set as a default and can be turned off within the privacy settings. Strava users can utilize the Strava heatmap to discover popular running, cycling, and swimming areas.  
 Even though users Heats Maps were anonymized, and it would be very difficult to correlate a certain persons heat map in hot spots where there are hundreds of heatmaps displayed, in some cases where these there are very few Strava users, it can become fairly easy to determine the identity of the users and their home locations based on the location of his heatmaps and via triangulation.**

**In 2018, a student from Australian National University found that the Strava heatmap highlighted the locations of military bases and outposts [5]. This issue has been addressed by national governments, not Strava, by restricting the use of fitness apps on military bases**

**-> Researchers targeted remote areas where a single user generated most of the heatmap activity**

** -> Used visual patterns to detect heat paths starting/ending at specific houses**

**After the 2018 Strava heatmap incident, where it was discovered that sensitive military locations (like U.S. military bases in Afghanistan, Syria, and Djibouti) were unintentionally revealed through aggregated fitness data, Strava faced intense public scrutiny—but no formal legal penalties were imposed by governments or regulatory bodies.**

**Ethical — Apple Heart Study (2017–2019)**

Apple and Stanford used Apple Watch data to detect irregular heart rhythms.

Over **400,000 people voluntarily enrolled** through their phones.

**Full transparency**, option to withdraw, ethics committee approval.

Apple showed that you don’t have to sacrifice ethics to get good results. By being transparent and respectful, they still managed to collect valuable health data at scale — and earned public trust in the process.

APPLE

**Slide 1: Apple Heart Study (2017–2019)**

**What Happened:**

* Apple and Stanford University partnered to **study irregular heart rhythms** using the **Apple Watch**.
* Over **400,000 participants voluntarily enrolled** using an app on their iPhones.
* Purpose: to evaluate if wearable tech can **detect atrial fibrillation (AFib)** and alert users before symptoms arise.

**Key Details:**

* Largest study of its kind at the time.
* Used **real-world, passive health monitoring** via consumer devices.
* Published in the *New England Journal of Medicine* (2020).

**Slide 2: Ethics Done Right**

**Ethical Strengths:**

* **Informed consent** was clear and easy to access.
* Participants could **withdraw at any time**.
* Study was reviewed and approved by **Stanford's Institutional Review Board (IRB)**.
* Data was **de-identified** and handled with strict privacy standards.

**Impact:**

* Demonstrated that ethical practices and large-scale health research **can coexist**.
* Helped validate **wearables as legitimate health tools**.
* Earned Apple and Stanford **public trust and credibility** in digital health research.

**Key Takeaway:**

Ethical transparency isn’t a limitation — it’s a strength that builds trust and still delivers meaningful scientific outcomes.