DATA PRIVACY MATTERS … *PERIOD.*

ORCHA REPORT ON THE DATA SECURITY OF PERIOD TRACKING APPS

Summer 2022

ORCHA

Introduction

Whilst more than 60% of people are advocates of using health apps, enjoying the convenience, immediacy and flexibility they provide, many are concerned about data security.[1] When asked why they might worry about using an app to support mental health, for example, 35% of people cite data security.[1]

Given the US Supreme Court's recent decision to overturn the constitutional right to an abortion, the data security of period-tracking apps is increasingly important. Such intimate data, revealing changes in the patterns of a person's menstrual cycle, could be used as evidence of a pregnancy.

That is why it is vitally important to understand an app's approach to data security.

The Organisation for the Review of Care and Health Apps (ORCHA) has been testing health apps for the NHS since 2015. It provides healthcare providers with a library of apps that have been tested against 350+ standards and measures, listing only apps which pass the 65% quality threshold, together with a summary of their evaluation results, including how they performed against data security criteria.

When it comes to data security, ORCHA assesses:

- Privacy policy
- Data sharing
- Personal data storage
- Encryption methods
- GDPR in the UK
- HIPAA in the US DHAF
- Consent
- User rights

ORCHA has assessed 25 popular period tracking apps against 350+ criteria, including the data security considerations. This is a summary of what ORCHA found:

Is sensitive information shared?

All of the period tracking apps collect personal data, such as name and contact details. They also gather sensitive information, such as period timings, and some apps track contraception and sexual activity as well. It may be inferred from this data whether or not a person is now - or has been - pregnant.

96% (24) the vast majority of the apps allow this data to be processed by the developer

84% (21) share the data beyond the developer's system to a third party

Only **1** app stores data only on the device, with no sharing functionality.

Following a 2021 settlement with the Federal Trade Commission over the alleged improper disclosure of sensitive user data, period-tracking app Flo recently announced a future "anonymous mode" feature to let users remove personal data such as names, email IDs and technical identifiers from their profiles.

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[1] https://info.orchahealth.com/digital-health-attitudes-behaviours-2022-report

Why do the apps share the information?

When asked, the apps report a wide range of reasons for data sharing, not primarily to deliver the service the patient wants and most commonly for marketing. But many do gather the information to help further services as a whole, gathering data for research or to enhance their service:

- **Marketing – 68%** (17)
- **Legal obligations – 64%** (16)
- **Research – 40%** (10)
- **Improving developer services – 40%** (10)
- **Payment transactions – 24%** (6)
- **Provision of Services – 17%** (18)
- **Performance of contract – 2%** (5)

Typically developers use third parties to sell the marketing contact lists. This information should be restricted to the personal contact information, not the sensitive information, but it does indicate that a user tracks their periods.

However it should be noted that after the overturning of Roe v Wade, some app developers have clarified that they do not sell data to third parties and placed an emphasis on data protection, promoting this fact via marketing channels and via notices in the apps themselves.
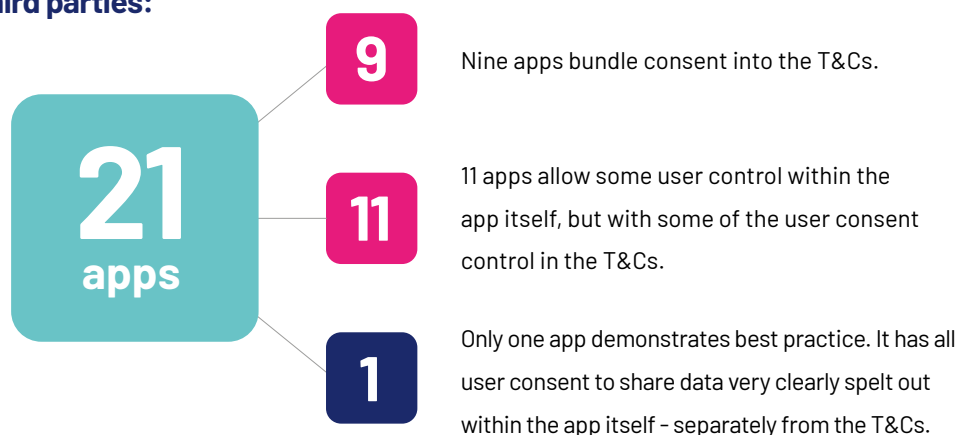
How are users asked for their consent?

Ideally, user consent to usage and sharing of data should be clear and available to adjust in the app, with each choice separated out, to enable the user to express their preference for each individual request. For example: usage of personal information, processing of financial information and sharing information to third parties.

However the industry appears to not adopt this approach. Instead, many wrap user consent into the overall T&Cs that the vast majority of people don't read. And even for the 1% of people who do, there is no ability to adjust preferences.[2]

Amongst the 21 apps that share data with third parties:

21 apps

9 Nine apps bundle consent into the T&Cs.

11 11 apps allow some user control within the app itself, but with some of the user consent control in the T&Cs.

1 Only one app demonstrates best practice. It has all user consent to share data very clearly spelt out within the app itself – separately from the T&Cs.

What are user rights?

By law, in the UK, Europe and the US, the app user can reclaim all data about themselves, know the third parties which have received the data, and request for all to delete the data.

So if an app user has accidentally ticked T&Cs, or if the app developer omitted to seek permission to share the data, there is a way forward and legal recourse. The app user should be able to very simply email or call the app developer about this. How to do this should be spelt out clearly in the T&Cs.

Yet five of the apps we examined do not include this basic information.

[2] https://www.digitaljournal.com/business/report-finds-only-1-percent-reads-terms-conditions/article/566127

Are period tracker apps meeting national standards?

National standards, such as GDPR in the UK and HIPAA in the US, are key regulations to ensure organisations inform users on how data is managed. Yet, of the apps that share data, half do not specify clearly that they comply with GDPR and almost half (13) demonstrate poor compliance with GDPR. One app failed to provide a privacy policy when processing special category data.

To be armed with the facts, ORCHA encourages users to read the short evaluation summary published alongside every app listed in an ORCHA library. Here you can read how an app performed against data security checks and be alerted to any concerns.

How many of these apps are trustworthy?

After assessing apps against data security requirements, just over half (56%) met ORCHA's minimum data security requirements.

However data security is only part of an ORCHA assessment. ORCHA also looks for professional assurance and usability and accessibility. After all, even if an app is secure, it needs to be effective. ORCHA looks for:

- **Professional assurance**: For example, ORCHA looks for registration with relevant regulatory bodies such as General Pharmaceutical Council (GPhC), Care Quality Commission (CQC) and MHRA; assesses if products need and have a CE mark, or are FDA cleared; searches for evidence scaled against the NICE Evidence Standards Framework; and assesses whether apps have safeguarding measures in place.

- **Usability and accessibility:** For example, ORCHA seeks to identify whether a product meets relevant app design standards such as WCAG 2.0 AA, WCAG 2.1 AA, ISO 9241, as well as looking at how users fed into the design of the product, accessibility settings and how support is provided.

With everything taken into consideration, it is clear that this is a market of low quality apps. Only 20% of the apps meet ORCHA's quality threshold. Many of the apps that do pass are not those with a specialised FemTech approach, but are the broader health apps with a simple and less sophisticated period tracking feature set. This is particularly worrying, given the high consumer demand for women's health apps and lack of regulation in app stores.

Only

20%
of the apps meet ORCHA's quality threshold

ORCHA Recommends

Two high scoring apps which demonstrate good practice across:

- Giving the user some control of data sharing (or at least not sharing by default)
- Demonstrating compliance with GDPR
- Including user rights in the T&Cs

Fitbit

Description:
This app helps you track sleep, stress and work outs, plus a myriad of other data, along with your menstrual cycle, so we'd view it as a generalist service for topline period tracking data only.

88%
Overall ORCHA Score
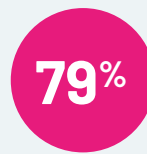
83% Data security

81% Usability and accessibility

97% Professional assurance

Natural Cycles

Description:
This is the only birth control app cleared by the FDA and also CE-marked as a medical device. It tracks your period and also basal temperature, so you know when you are fertile and most likely to get pregnant.

79%
Overall ORCHA Score

82% Data security

75% Usability and accessibility

79% Professional assurance

Please visit your local health app library and search for 'period tracker' to find apps that meet the threshold, and also understand more about how they handle data.

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