# PACE Project: Fertility & Menstruation Apps – Internal Report

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### **Executive Summary**

Following a considerable history of concerns being raised about fertility and menstruation apps, this PACE project was established in May 2023 to explore the hypothesis (Problem Statement) that 'fertility and period tracking apps are misusing user data in a way which causes harm'. The project had three principal objectives:

1) to understand how selected apps use data, identify any data protection (DP) non-compliance, and capture areas of DP good practice;

- 2) to explore ways to identify harms (or risk of harms) potentially arising from DP non-compliance and establish if there are causal links or potential causal links; and
- 3) to recommend action that ICO should take to minimise harms or promote good practice in the sector.

This paper summarises the project's work to fulfil these three objectives and evidences how they have been achieved.

In summary, we do not have evidence that apps are misusing user data, specifically their sensitive personal information relating to menstruation and fertility, in a way which causes harm. We have, however surfaced a number of compliance concerns around obtaining user consent, the lawful bases being relied upon, and the transparency of data processing, together with a commensurate naivety and lack of user engagement or concern with how apps process their personal data, which arguably allows poor privacy practices to perpetuate 'under the radar'. These issues are not considered to be unique to the fertility and menstruation app industry and, it is recommended that no formal investigative action is taken against the apps who engaged with us on this project. Instead we recommend:

- awareness-raising among app users of their data protection rights and what they should look for in choosing a data protection compliant app; and
- ii. bespoke advice and guidance to the app developers we have engaged with on this project, alongside a wider education piece targeted at all app developers reminding them of their data protection obligations, would empower and protect users and improve best practice amongst app developers

## Background

### Origin

Concerns about fertility and menstruation apps were first considered by the ICO in 2019, following an investigation by Privacy International (PI)<sup>1</sup>. PI raised concerns about the data sharing practices of various menstruation apps and made a number of recommendations, including calling on action from regulators. In December 2020 PI published further findings as part of the same campaign<sup>2</sup>. This report was featured in the Guardian<sup>3</sup> and renewed public and media interest in these apps and their processing of sensitive data.

<sup>&</sup>lt;sup>1</sup> No Body's Business But Mine: How Menstruation Apps Are Sharing Your Data | Privacy International

<sup>&</sup>lt;sup>2</sup> We asked five menstruation apps for our data and here is what we found... | Privacy International

<sup>&</sup>lt;sup>3</sup> Menstruation apps store excessive information, privacy charity says | Menstruation | The Guardian

In November 2020, the ICO received a complaint regarding

The data subject (DS) was concerned that upon upgrading to a new mobile phone, their personal data appeared to be lost and that the app no longer recognised their account/email address, despite them having a premium subscription to the app. In response to the DS,

advised that users can access the app anonymously and that the DS's email address was not registered against their account, therefore they are unable to provide the data. There have been no further complaints reported following this.

Civil Investigations subsequently commissioned Intel to produce two briefings on fertility and menstruation apps (<u>January 2021</u> and <u>November 2022</u>) on account of concerns raised in media articles regarding potential collection of special category data, user profiling, sharing of sensitive data with third party partners, and limited transparency of processing and compliance controls.

In December 2022 Intel published its <u>Strategic Assessment</u>, and identified 'online tracking' as one of the ICO's Regulatory Priorities. It discusses aims for individuals to be able to trust that their rights will be respected when using online services, which is made more difficult with the invisible processing of personal data that comes with online tracking. Fertility and menstruation apps are specifically identified within this paper as an area of potential interest and priority for the ICO. In the same month, the ICO's inaugural <u>Tech Horizons Report</u> was published, highlighting a shortlist of technologies which present the most impactful and novel challenges for data protection. One such technology is 'consumer healthtech', and a specific mention of 'fertility tracking apps'.

In January 2023 Civil further referred the issue to the then Development and Coordination Unit (DCU) following media articles raising concerns about fertility and menstruation apps collecting large amounts of personal data and sharing it with third party organisations including advertisers and Facebook. HPI was subsequently (March 2023) tasked with conducting scoping work into fertility and menstrual apps, and in May 2023 the workstream was designated as a PACE project.

This project also links to the ICO's strategy to address harms arising from non-compliance in the adtech eco-system. The initial phase of strategy identified four broad areas of focus for consideration of such harms, namely discrimination, health, children, and vulnerable groups, with the intent that a cross-office project be taken forward in each area to tackle

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the harms identified. This PACE project was proposed in the area of health, with the hypothesis that '(F)emale health related websites and apps are sharing intimate health data (potentially special category data) with adtech intermediaries without sufficient transparency, purpose limitation or governance.'

### Decision to focus on fertility and menstruation apps

In April 2023 Intel proactively produced a <u>Problem Profile on FemTech and women's health apps</u>. Noting that the 'FemTech market' covers a much wider range of women's health apps than solely fertility and menstruation apps, it was suggested that the scope of the project be broadened to consider women's health apps more broadly. The decision was made, however, to restrict the focus of the project to so-called called 'period tracking apps' in light of time and resource constraints; external interest (in the media and by privacy and consumer rights groups) having been focused on fertility and menstruation apps; and data compiled by Intel from the Google Play Store indicating that the most globally downloaded apps across the FemTech sector are fertility and menstruation apps.

### Definition

For the purpose of the project, 'fertility-tracking apps' and 'period-tracking apps' are defined as follows:

"Mobile applications with a focus on women's fertility or menstrual health which provide tools for users to track their menstrual cycles, ovulation, or fertile windows. They may have additional content which is connected to other relevant aspects of women's health, such as pregnancy or menopause, however, the primary purpose of the apps related to fertility or menstruation."

Furthermore, the project focuses on *downloadable* apps, rather than apps that are available by default (such as 'Cycle Tracking' available within the Apple Health app). This decision reflects both a lack of concerns raised in relation to these apps and that the menstruation tracking function is not the primary purpose of such general health apps.

### **Problem Statement**

The Project Outline shared by the then DCU made reference to the fact that available complaints data related to this subject are limited, and that it was not currently clear whether data is being misused and/or whether this is resulting in any wider harms. Concerns were highlighted, however, that there is potential for:

- excessive collection of special category data;
- profiling of users;
- sensitive data being shared with third party partners;
- limited transparency on processing practices;
- limited ability to exercise information rights; and

potentially harmful personalised ads targeted at users.

It was also recognised that there is a strong gender-based angle to the project, with the potential in particular for misuse of women's highly personal data at a vulnerable point in their lives, such as infertility, miscarriage and menopause.

As such, the following Problem Statement was developed:

# There are concerns that fertility and period tracking apps may be misusing the data of its users in a way which causes harm.

### **Project Objectives**

Three objectives were identified; the component initiatives of Objectives 1 and 2 are also set out below:

• **Objective 1:** Understand how selected apps use data; identify any DP non-compliance; and capture areas of DP good practice.

### Key initiatives:

- Make an informed decision on which apps are within the scope of this work.
- Obtain adequate responses from the apps explaining how they use data (voluntarily or through use of powers).
- Receive feedback from users on their positive and negative (data protection) experiences using the apps. Understand from users how their experiences align with explanations provided by the apps.
- Get insights from regulators and third parties on positive and negative practices of the apps (and how their experience with other apps may inform our action).
- **Objective 2:** Explore ways to identify harms (or risk of harms) potentially arising from DP non-compliance and establish if there are causal links or potential causal links.

### Key initiatives:

- Gain understanding of the ease of buying relevant audience data in the adtech market, and of a potential correlation or causal link between downloading the app and receiving harmful adverts.
- Obtain insights of user experience which increase our understanding of experienced harm.
- Receive insights from regulators, third parties and the media on harms or risk of harms by the apps.
- **Objective 3:** Recommend action that ICO should take to minimise harms or promote good practice in the sector.

### **Workstreams Initiated**

Work initiated to fulfil the three objectives set out above can be categorised into the following eight workstreams:

- 1. Open Source Research (OSR) general research and review of media, available apps, and academic articles.
- 2. Engagement with app providers including decisions on which apps to contact.
- 3. Engagement with external stakeholders interested parties, such as other regulators, academics, and civil society groups.
- 4.
- 5.
- 6. ICO Poll to gain a high-level overview of how widely periodtracking apps are used, and users' considerations when choosing an app.
- 7. ICO external survey to understand users' views of these apps.
- 8. Commissioned third-party research to understand users' perspectives and use of fertility and menstruation apps

Each of these is reviewed in turn below, along with a summary of our findings/outcomes.

### Review of Workstreams & Outcomes

1. Open Source Research (OSR)

### Objective 1

Since March 2023, and on an ongoing basis, a huge amount of scoping and open-source fact-finding has been undertaken in pursuit of understanding the period-tracking app industry and its eco-system (Objective 1). This has included review of media and academic articles and associated literature, and papers authored by Privacy International.

At the outset, two mobile apps were identified by the then Development and Coordination Unit (DCU)

The November 2022 Intel

Briefing identified 28 fertility apps, 49 menstrual apps, and 30 combined fertility and menstrual tracking apps, with a number of apps appearing on both the 'fertility' and 'menstruation' app lists on account of their functionality. This same report identified the 'period-tracking' apps with the highest number of downloads (at the time of writing) on the UK Google Play Store: eight apps had download figures ranging between 10 and 100 million. Although it is unclear what proportion of the downloads related to UK citizens, the figures were assumed to be representative of widespread processing across the UK population also.

In total, 37 apps were reviewed by HPI. These apps were variously highlighted in the Intel Briefing/list of downloads, or flagged by media and/or academic articles reviewed as part of the team's scoping activity. In sum, 11 media articles and 14 academic papers were reviewed, providing a thorough understanding of the period-tracking app industry and commentary and research into it.

This background research raised a number of potential concerns with the data and privacy practices of menstrual and fertility tracking apps, including:

- Excessive collection of data (including special category data) and the lawful bases for processing this data ('purpose limitation')
- Compliance with the principle of 'data minimisation'.
- Profiling of users
- Sensitive data being shared with third party partners
- Limited transparency of processing practices
- Limited compliance controls (eg responding to Subject Access Requests (SARs); retention and deletion)
- Adequacy of security measures to protect sensitive information

It is noteworthy that only 10% of the FemTech market is UK-based.

As such, scoping work identified the considerable risk that entities based outside of the UK are processing UK citizen data with the potential for harm.

Subsequently, engagement with a cross-section of app providers was initiated to gather detailed information in relation to the concerns outlined above and to further fulfil Objective 1.

2. Engagement with app providers

### Objective 1 / Objective 2

In order to meet Objective 1, consideration was given to which, and how many, apps to engage with. Considerations included the team's capacity to carry out sufficiently informative (detailed) enquiries (ie it would not be feasible to contact all the app providers identified/reviewed to date); the need to ensure enquiries were representative of period tracking apps of all sizes (not just the larger organisations/most downloaded apps; apps with fewer downloads (perhaps on the basis of negative reviews or lower ratings) may pose a greater risk in terms of handling and/or safeguarding users' personal data); and jurisdictional reach

) – but to only target UK-based providers

would potentially not be representative of the apps that UK citizens use in practice.



On account of this additional research, it was agreed that 11 apps would be contacted as follows:

- based on a review of the apps researched during OSR scoping to date, three priority apps where potential compliance issues have been flagged; and

This selection was considered to cover a variety of apps across the landscape, enabling the project to engage with those identified through OSR alongside the apps with the highest UK download figures

Issuing targeted and focused enquiries to 11 apps was considered to be feasible within the project's resources and would allow for themes identified to be explored in sufficient detail. A list of the apps selected is

provided in <u>Appendix 1</u>. The apps are not specifically referenced within this report as the intention was not to investigate particular apps, but rather to make enquiries into the data processing activity of such apps with a view to establishing the *types* of behaviour represented across the sector.

Indeed, in writing to the 11 app providers, we made it clear in our correspondence that:

The ICO is currently looking into the personal data processing activities of fertility and menstruation apps. As part of this work we are making fact-finding enquiries with a number of organisations, including [XXX].

We are not actively investigating a contravention of the data protection legislation. As this stage, we are primarily interested in understanding the processing activities arising in connection with the use of fertility and menstruation apps.

We did include the caveat, however, that if breaches of data protection legislation were to be identified during the course of enquiries, the ICO would need to consider what action, if any, is required, in line with our Regulatory Action Policy.

The information requested of each app was as follows:

- 1. Please describe the functions of the app.
- 2. Please provide details on the personal data processed by the app:
  - a) What types of personal data are processed?
  - b) Please identify any special category data processed.<sup>5</sup>
  - c) Please confirm what data fields are optional to users.
  - d) Please also specify which data fields are mandatory, and the reason for the mandate.
- 3. Please confirm what demographic information you hold about users of the app.
- 4. Please detail how you ensure that the personal data being processed is relevant and limited to what is necessary for the purposes of the app.
- 5. What lawful basis have you identified for processing personal data?<sup>6</sup>
- 6. If relevant, what condition for processing special category data have you identified?

<sup>&</sup>lt;sup>5</sup> https://ico.org.uk/for-organisations/uk-gdpr-guidance-and-resources/lawful-basis/special-category-data/what-is-special-category-data/

<sup>&</sup>lt;sup>6</sup> https://ico.org.uk/for-organisations/uk-gdpr-guidance-and-resources/lawful-basis/

- 7. Do you share users' personal data with any third parties? If so, please provide the following details in relation to each third party:
  - a) Name of the third party.
  - b) What personal data you share with that third party, and how it is shared.
  - c) Reason for sharing personal data with that third party.
  - d) Confirm whether the third party is a controller or a processor.<sup>7</sup>
  - e) Provide a copy of any data sharing, and/or controller/processor agreement you have in place.
  - f) If different to that identified at question 5 above, confirm the lawful basis you rely upon to share the data.
- 8. If you rely on users' consent to process or share their data, please provide examples of user interface screenshots or user journeys that show when and how you seek their consent for this. Please also provide examples of user interface screenshots or user journeys that show how users can withdraw their consent.
- 9. Do you share any anonymised data with third parties? If so, what privacy enhancing technologies do you use to achieve anonymisation?
- 10. Please provide copies of any privacy information you provide to users about the collection and use of their personal data. Please also provide examples of user journeys or user interfaces that show how privacy information is presented to users.
- 11. Do you carry out any profiling of users, in line with the definition for profiling set out at Article 4(4) of the UK GDPR?<sup>8</sup>
- 12. Please provide details on how the data is stored, and whether it is stored on a server or on a user's device.
- 13. Please describe the measures you have in place to ensure the security of users' personal data?
- 14. For how long do you retain users' personal data?
- 15. Do you provide a way for users to exercise their individual data rights?<sup>9</sup> If so, please provide examples of user journeys or user interfaces that show how users can make requests for:
  - a) access to copies of their personal data,
  - b) rectification of inaccurate or incomplete personal data, and/or

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<sup>&</sup>lt;sup>7</sup> https://ico.org.uk/for-organisations/uk-gdpr-guidance-and-resources/controllers-and-processors/

<sup>&</sup>lt;sup>8</sup> <a href="https://ico.org.uk/for-organisations/uk-gdpr-guidance-and-resources/individual-rights/automated-decision-making-and-profiling/what-is-automated-individual-decision-making-and-profiling/">https://ico.org.uk/for-organisations/uk-gdpr-guidance-and-resources/individual-rights/automated-decision-making-and-profiling/</a>

<sup>&</sup>lt;sup>9</sup> https://ico.org.uk/for-organisations/guide-to-le-processing/individual-rights/

- c) erasure of their personal data.
- 16. Please provide details of any data protection complaints you have received.

If you have any further information relevant to this matter, please provide full details when responding.

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The team received responses from ten of the 11 app providers, without the need to serve Information Notices (IN) –

This is considered to be a very positive outcome with app providers clearly signalling their

to be a very positive outcome with app providers clearly signalling their willingness to engage with the ICO's work in this space.

Detailed reviews were conducted of the app responses, with initial findings pointing to excessive data collection, inappropriate lawful bases being relied upon/failure to obtain valid consent, a general lack of transparency, inadequate security measures and an overall lack of accountability. Further review enabled the team to categorise potential compliance concerns in nine areas; namely: data minimisation; lawful basis for processing; gaining valid consent; transparency of processing (privacy notice); security of data/processing; data retention; ability for data subjects to exercise their rights; data sharing; and accountability.

The table below provides a visual overview of the potential compliance concerns identified across the ten apps in the nine areas listed. It represents holistic impressions formed from our review of enquiry responses and should not be interpreted as evidence of a breach or confirmed compliance concern. It should also be noted that the app enquiry responses provided varying levels of detail and so it has not always been possible to make direct comparisons across compliance areas, nor do the concerns (X) recorded in the table necessarily represent the same degree of concern and thus are not directly comparable. Where app providers showed a willingness to engage and provide more detailed responses than others, for example, this may have resulted in more concerns having been identified (or a more accurate assessment of particular concerns) compared to app providers that responded in less detail.

The app providers have been anonymised for the purposes of this report, which is to indicate potential compliance concerns/harms across the industry as a whole, and not the performance of specific apps. NB.

Potential compliance concerns										
App ID	1	2	3	4	5	6	7	8	9	10
Location										
UK downloads										
Global downloads										
Data minimisation										
Lawful basis										
Consent										
Transparency										
Security										
Retention										
Individual rights										
Data sharing										
Accountability										

X = potential compliance concern

? = further information would be required to judge this ✓Blank = no concerns identified from direct engagement

As the table shows, the performance of individual apps against certain criteria varies considerably. It would be unwise, however, to attempt to link popularity (as measured by number of downloads) with rates of observed compliance, or to suggest that one app performs much better than another given the variability in response detail etc - nor was this an aim of the project. Rather, this overview of the fertility and menstruation app industry based on a cross-section of apps selected to represent (but which is not necessarily representative of UK usage) indicates that there are systemic issues regarding the lawful bases being relied upon by apps and a failure to obtain valid consent for processing, coupled with a general lack of transparency about the data processing at hand (including sharing with third-parties) and how

# the apps comply with the principles of UK GDPR (as addressed by their Privacy Notices).

The app providers gave a variety of purposes for processing data in their responses to our initial enquires and within their respective privacy policies. It is our assessment that sharing of data relevant to menstruation and period tracking, health and/or special category is only shared for purposes relating to storage, security, cycle prediction functionality, and customer support. In these cases, the apps identify explicit consent as the Article 9 condition to process. There is no evidence that the apps are sharing sensitive data for advertising purposes. Not surprisingly, other personal data, including IP address, device data, usage data, and advertising ID, is shared by some apps for advertising and marketing purposes. In most instances, we can conclude that these third parties are data processors and, therefore, are acting strictly on the instructions of the app developer. Two responses confirmed that some third parties are controllers, and all third-party data controllers in these cases are engaged for advertising purposes. None of the data shared with these parties, however, consists of personal data input by users.

Engagement with users (as summarised in Sections 6 to 8) was designed to add more colour to the technical operation of the app (ie 'lived experience') and to identify potential harms arising from the potentially poor practice of the apps as identified above.

### 3. Engagement with external stakeholders

### Objective 1 / Objective 2

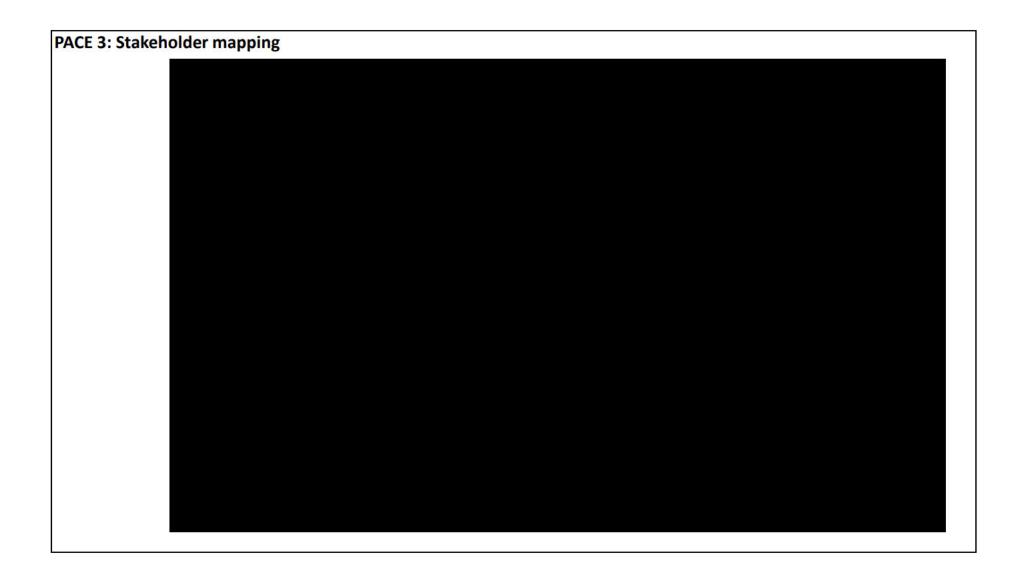
An external stakeholder analysis was undertaken in June 2023 in order to put relevant bodies and organisations 'on notice' that the ICO was exploring the data protection compliance of the fertility and menstruation app industry, and to encourage their engagement with this project.





The team also engaged with the ICO's own Women's Network (although this resulted in 'for info' only engagement given legal concerns with receiving data from employees/lack of clarity as to what the benefits of receiving such data may be) and ICOR to establish if there were any specific regional issues (none identified).

A comprehensive overview of the stakeholder mapping exercise and the relationships between specific entities is illustrated on the following page.



The team engaged with eleven entities more substantively, the highlights of which are summarised below.

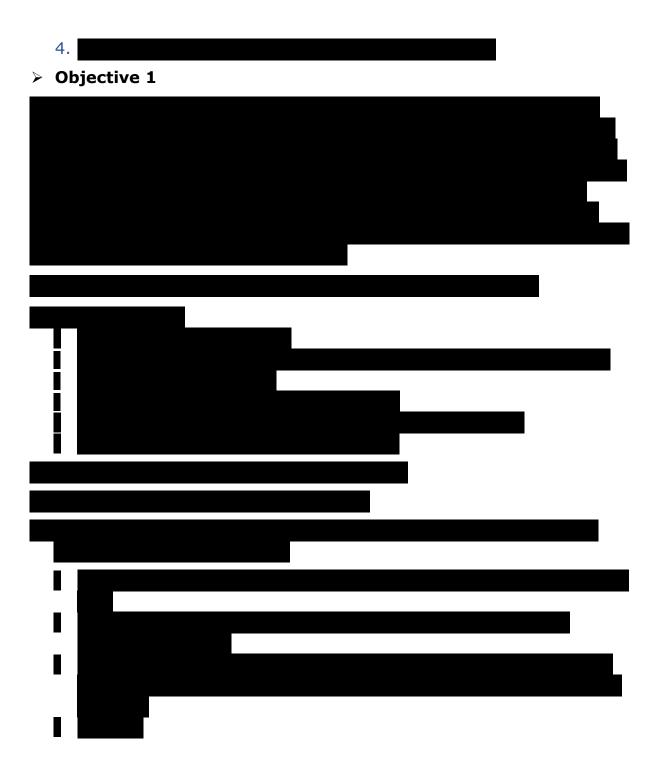








In summary, our engagement with the stakeholders summarised above did not progress the project in any substantive way but did confirm that the purported harms associated with such apps are challenging to categorically evidence and unequivocally link back to use of the app. There do not appear to be major privacy concerns among app users, but where poor practices are identified, they pertain to transparency of processing, issues around user consent, and potential third-party data sharing.







<sup>&</sup>lt;sup>11</sup> Right to be informed | ICO







### 2. ICO Poll

### Objective 2

As a precursor to more detailed research into users' experience of period-tracking apps (part of Objective 2), ICO commissioned a poll from Savanta<sup>12</sup> to ascertain why women use such apps (if at all), and what considerations they have (or would have) when choosing which app to use. Between 1 and 3 September 2023, 1,152 UK women aged 18+ were surveyed. Data was weighted to be representative by age, gender, region, and social grade.

Respondents were asked the following three questions:

- 1. Have you ever used an app to track any of the following [select all that apply]?
  - a. To track your period
  - b. To prevent a pregnancy
  - c. To plan a pregnancy
  - d. None of these
- 2. When choosing an app to track periods or to plan or prevent a pregnancy how concerned would you be about each of the following? [5 point scale from very concerned to not at all concerned]
  - a. Ease of use
  - b. Cost
  - c. Volume of adverts within the app
  - d. Volume of personal data I needed to share
  - e. Type of personal data I needed to share
  - f. Security of the data I was sharing
  - g. Transparency over how my data is being used and shared
- 3. If you have ever used an app to plan or prevent a pregnancy, did you notice an increase in online advertising about baby or fertilityrelated products and services?
  - a. Yes and this was positive for me
  - b. Yes and this was distressing to me
  - c. Yes and this was neither positive nor distressing
  - d. No
  - e. Not sure

The poll showed that a third of women have used apps to track periods or fertility, and women said that transparency over how their data was used

<sup>&</sup>lt;sup>12</sup> Savanta is a member of the British Polling Council and abides by its rules.

(59%) and how secure it was (57%) were bigger concerns than cost (55%) and ease of use (55%) when it came to choosing an app. Volume of adverts within the app were of least concern (21%). Nevertheless, the research showed over half of people (54%) who use such apps believed they had noticed an increase in baby or fertility-related adverts since signing up: 17% described receiving these adverts as distressing, with approximately the same number of people (18%) saying it was positive.

The results of the poll were published on the ICO website, <sup>13</sup> and was picked up by print and online newspapers (<u>Guardian</u>; <u>Telegraph</u>; I; <u>BBC</u>; <u>Independent</u>; <u>Times</u>; <u>Mail</u>; and <u>Evening Standard</u>) and was broadcast on the BBC News at Ten, BBC Radio 5 Live Drivetime, BBC Radio 1 Newsbeat and BBC Radio 4's World at One. It also did well on social media, with the ICO's highest reach content on Twitter for the previous two weeks, as well as showing good reach, positive engagement and shares on Linkedin.

The results of the poll were also used to introduce ICO's work to the wider public and to launch a call for evidence with users of such apps asked to share their experiences directly with the ICO via a survey (see Section 7 below). The media coverage was significant in highlighting our work both to the app industry and to the public, and provides the foundation for further comms work on the project.

### 3. ICO external survey

### Objective 1 / Objective 2

On publication of the poll results, a 'call for evidence' was launched to gather more detailed insights into how personal information may used by period and fertility tracking apps (Objective 1) and users' experiences of using such apps (part of Objective 2). This survey was open from 7 September to 5 October 2023 and sought to understand whether users had experienced harmful consequences from, or be negatively impacted by, the way their personal information is used or shared by these apps, as well as whether there were examples of good practice in the way these apps handle personal information.

Respondents were asked three questions, and invited to leave their name, email address and age (all optional fields) if they were willing to be contacted by the ICO in order for us to learn more about their experiences or to invite them to be part of a case study.

- 1. Have you had a positive or negative experience around the use of your personal information by period tracking apps or fertility tracking apps?
  - Completely positive

<sup>13</sup> <u>ICO</u> to review period and fertility tracking apps as poll shows more than half of women are concerned over data security | ICO

- Mostly positive
- · Neither positive or negative
- Mostly negative
- Completely negative
- 2. Please give details of any positive or negative experiences around the use of your personal information by period tracking apps or fertility tracking apps. Please name the app or apps involved.
- 3. How did this experience affect your usage of the app?
  - I used it more
  - It did not change my usage
  - I did not stop using it but I did use it less
  - I stopped using it and found an alternative app
  - I stopped using period/fertility tracking apps
  - N/A

Participants were advised that the ICO would not be resolving individual concerns and submissions would not be treated as complaints to the ICO – but were signposted to how to make a complaint.

187 responses were received from individuals aged 17 to 52. While this is considered to be a good response rate, the survey should be regarded as qualitative in nature (several thousand responses would be required for the research to be considered quantitative in nature and representative of the app user population). Nevertheless, 64.5% of respondents considered their experience of fertility and menstruation apps as positive, with the experiences of the majority of respondents (70.1%) not negatively impacting on their usage. Indeed, 43.5% confirmed that their experience did not change their usage, and 26.6% used the app more. It is important that we recognise, therefore, that menstruation and fertility tracking apps are associated with valid objectives of promoting menstrual literacy and encouraging self-knowledge. Furthermore, used as reproductive technology, fertility tracking apps often appear to have a positive impact when used by an individual aiming to facilitate pregnancy. However, there is a need for this to be done in compliance with data protection legislation and without harm and detriment to data subjects.

. Good

practice/positive feedback on the apps referred to by users included: accurate cycle predictions and being user-friendly ("I have found it useful and extremely accurate for my cycle" and "Really useful and simple to use"); respondents also suggest that descriptions about how their data are used are clear and that they have control over their data and the purposes for which is it processed (eg opting out of personalised ads) ("They have a good section and description about how they use my data" and "The app has been so helpful to me and I feel it communicates clearly

how my data will be used"); choosing only to share the data they felt necessary to gain the functionality they needed ("I have limited the data I have decided to share with the app, only sharing what I felt was necessary to gain the functionality I needed"). There was also positive commentary on being able to exercise their rights as data subjects, for example requesting erasure (and this being actioned in a timely manner -"After submitting a deletion request, this was honoured by the company and within the regulatory period. I was regularly updated. This was a positive experience following concerns I had for the use of my data.") and being able to export their data ('data portability' -"Easy to use, keeps everything logged, you can export it straight onto a excel sheet"); not receiving any targeted adverts attributable to data they have used in the app ("There are no ads in the app, but also no apparent data leakage as I don't get any ads elsewhere that appear to be targeted based on my menstrual data"); and a general feeling that their data is secure ("I fully trust the data storage of this app").

Despite some users reporting an absence of targeted ads as a positive aspect of their app usage, over 30 responses cited concerns vis-à-vis receiving personalised/targeted ads that were either unwelcome (conception related, when the user is merely interested in recording their cycle – "I have zero interest in having children but have received a lot of advertisements about conception and baby products since using [app name]") or insensitive/upsetting (eg having logged a pregnancy that subsequently miscarried – "All I have gotten from it are constant fertility adverts which has definitely affected me negatively."). There were similar concerns around unsolicited marketing ("I did not sign up for marketing communications directly from it. I noticed a big up-tick in marketing (on social media platforms), some direct emails from unknown companies all around fertility and pregnancy."), and potentially unlawful data sharing ("The answer to my access request reveals that my data has been shared with entities I did not specifically consented to.").

It is apparent from the responses that there are considerable differences between apps. While being able to exercise control over personal data input into the app was cited as a positive by some, others suggested their app required them or allowed them to log other personal details which do not seem relevant to the purpose of, for example, period tracking (excessive data collection – "The app also allows users to log other details including period flow intensity, symptoms (eg headache, hot flashes, cough), mood, sexual intercourse (protected or unprotected), ovulation test results, fluids (egg white, creamy, sticky, unusual) and whether the morning after pill was used. There does not seem to be any value in logging this highly sensitive special category data"). Similarly, some respondents raised concerns around how difficult it was to have their data erased ("I found it a little difficult to delete my data from [app name] when I felt that I wanted my data to be deleted."); unsatisfactory

responses to their access requests ("I requested access to my data, they sent me the answer on the last day of the 1 month term on a password protected document without the password. I had to send another email to receive the password."), and an inability to edit their data ('rectification'). There was also commentary on how untransparent the apps are in relation to how users' data is processed ("It is not transparent in how it uses my data at all. I have no clue what it does with it and feel I would have to be a lawyer to understand.")— despite transparency being flagged as a positive by others.

The survey has provided a useful overview of the public's perception of fertility and menstruation apps, which is generally (if not exclusively) positive. Such apps appear to be an important/useful tool for many women but there may be a need for some of these apps to improve the ways in which they uphold users' privacy rights and comply with the legislation. The concerns flagged, while unevidenced and anecdotal, do correlate with a number of areas of questionable compliance among the apps the project has engaged with directly, namely: transparency, and what a user may or may not have consented to within the app, including third-party sharing.

### 4. Commissioned third-party research

### Objective 2

In addition to the ICO's survey (see <u>Section 7</u> above), the ICO commissioned a piece of external research to set up and facilitate a number of focus groups and 1-2-1 interviews (including with lapsed users) to gain an accurate understanding of the public's experiences of these apps, including any concerns they have about them.

A research specification was put out to tender with four external organisations, setting out the following research objectives:

- Overall views on fertility and menstruation apps, benefits and concerns about using these apps.
- Awareness of data protection concerns relating to the use of these apps.
- The amount of data that users input into their fertility and menstruation apps from sign-up to during use.
- How easy users feel it is for them to exercise their data rights while using the apps.
- Users' understanding of how their personal information is used when they enter it into these apps.
- Users' reactions to finding out what could happen to the data they enter into fertility and menstruation apps
- Knowledge and understanding of privacy policies and users' approach to this when signing up for these apps.

Three proposals were received, and the work was awarded to IFF Research Limited.

Ten interviews were carried out, comprising three lapsed users and seven current users of such apps, and covered: reasons for selecting their chosen app; ways in which they use/used the app; their opinions on the sign-up process of a different app (by taking part in a 'walk-through'); and their general views on data privacy in relation to their current app. In addition, two focus groups were carried out: one with individuals who use apps mainly for period tracking; and the other with subjects who use such apps for fertility tracking. The focus groups covered: reasons for selecting their chosen app; ways in which they use/used the app; general attitudes to data privacy; and their attitudes to data privacy vis-à-vis period/fertility tracking apps.

As a piece of qualitative research it is important to note that although the findings are *indicative* of views across users of a range of period and fertility tracking apps they are not necessarily *representative* of app users. Participants were invited to take part in the research through an 'opt-in' process, such that the sample is self-selected. Having agreed to take part in (market) research on menstruation and fertility apps, it may also be the case that these individuals are less intrinsically private. Although the sample was in no way weighted toward users with positive experiences, it does not include individuals who have never used such an app (and their potential concerns about data usage).

### The research concluded that:

- Users are generally very positive about using fertility and period tracking apps, with the benefits outweighing any concerns they may have with a particular app. Most had signed up to the apps through recommendations from friends, with a few users who were tracking for fertility purposes indicating that they had been recommended this by consultants/doctors/specialists.
- There is very little concern among users around *how* fertility and period tracking apps use their data, with no unprompted mentions of data security or privacy. None of the lapsed users interviewed had stopped using the apps due to privacy or data concerns.
- Users are generally not concerned about their information being 'leaked' or sold to third parties as it's not identifiable, nor do they consider it to be as sensitive as the information other apps may hold on them (eg banking apps); users were happy to enter lots of personal health information into the app to get most out of the app.
  - "I don't have any concerns. I don't put enough sensitive information in it. I'll talk to anyone about my period... I don't know why they'd need to steal period tracking data"
- There is an assumption that the apps are validated as being 'safe' or 'approved' by virtue of being available on the app store, and this

was linked to low user engagement with privacy policies and how apps use their data. Users are trusting with how these apps use their data, with recommendations and ratings on the app store contributing to their lack of concern around data security. "I think because it has to be so watertight at the moment, it's been checked by so many lawyers and people before it even gets into an app and then onto the Apple platform... But I think some people might want to read it because it's a personal topic."

- When specifically prompted, some users indicated that they 'probably should' engage more with the privacy policy; similarly, most users said they thought that they must have been shown something during the app sign-up process and just ticked 'yes', but no-one recalled any detail of what they were shown.
- When running through the app walkthroughs during the in-depth interviews, no one clicked on the privacy policy to read it unprompted. "I'm guilty of not reading any of the terms of service or any policies. I tend to just agree. I tick agree and sort of yeah, keep moving, I don't have the time."
- It appears that users would engage more in information about how an app uses their data if this was presented in a short and simple format, but many users don't have the appetite to investigate how their data is used.
- In general, there are low levels of knowledge regarding how fertility and period tracking apps process user data, although individuals tended to assume that the app would use their data for targeted advertising (the 'era we live in') and for making improvements to the app itself and generally assumed they had agreed to this at some point in the sign-up process or that somewhere in the app it told them that information was being shared.
- Some users were critical of their fertility tracking app using their data for targeted advertising because of sensitivities around fertility issues; others simply found targeted adverts annoying but inevitable.

There is some correlation between the findings of this qualitative research and both the ICO's initial poll (quantitative) results and follow-up survey. (see above).

- Although transparency was flagged in the poll as an important consideration in choosing an app, this was not mentioned in the third-party research. Nevertheless, when transparency was explored with participants, there were mixed views on whether the apps were transparent – which correlates with responses to the ICO's own survey.
- Similarly, although the poll results suggested security of data is (or would be) important to users, this was generally not a concern of users in IFF's study. This may stem from the fact that the subset of

- users who participated in the third-party research did not consider the data they inputted into such apps to be particularly sensitive.
- Users of the apps in the ICO poll and IFF research noticed an increase in fertility-related ads since signing up for an app, but the participants of the focus groups struggled to explicitly attribute this to the app itself as they were also actively 'googling' related topics. Of more concern, perhaps, is the suggestion that the content of some of these targeted adverts is insensitive (as reflected in responses to the ICO poll and ICO survey).

Having solicited user feedback through three separate modes, it is apparent that users are generally positive about using fertility and period tracking apps, and the perceived benefits outweigh any concerns they may have with the app and how it may use their data. There is, however, a degree of potentially misguided trust and naivety about how these apps are validated for use (on the app store), particularly as some users are being recommended such apps by medical practitioners. A lack of user engagement with app privacy policies suggests that app providers are able to perpetuate poor privacy practices 'under the radar'. These poor practices cannot be linked to causing explicit harms in the user population but are widespread enough to suggest that awarenessraising among app users of their data rights, and an education piece among app developers reminding them of their data protection obligations could empower users and hold app developers to account in a way that they are not currently.

### **Summary of Findings**

The team's OSR work indicates that fertility and menstruation apps are a subject of interest with considerable attention and coverage in a number of different areas. Legitimate concerns have been raised about the data processing taking place.

Have fertility and period apps been misusing people's personal information?

We do not have evidence that period and fertility apps named in this report are misusing users' sensitive personal data relating to menstruation and fertility in a way which causes harm.

We do not have evidence that the apps are sharing special category data for unjustified purposes, nor sharing special category data for the purposes of advertising.

Where special category data is shared for other purposes, the relevant apps correctly rely on explicit consent.

Users are generally positive about the use of period and fertility apps, and profess to not being overly concerned about the data they input in the app, or how it is then processed by the app. Users expect their data to be shared and consider receiving targeted adverts to be a by-product of their app usage, especially when the app is free to download.

We have reached this conclusion following a detailed review of the responses received from the app providers and their respective privacy policies .

This is also corroborated by the feedback from our user engagement activities.

### Other issues raised

Where apps share personal data that is not special category, based on their legitimate interests, this sharing falls within users' reasonable expectations of processing, and no harms have been identified. In some cases this data sharing is not made sufficiently explicit, however improvements in this regard can be made through targeted engagement rather than enforcement.

Users confess to not engaging with the privacy notices of the fertility and menstruation apps they use. While this does not absolve app developers of their data protection and accountability obligations, a lack of user engagement has arguably allowed such practices to proliferate and go unchecked. This is likely to be symptomatic of app usage more generally and not specific to fertility and menstruation apps. We found there to be a lack of transparency or insufficient information on data processing and, consequently, a reliance on bundled consent declarations.

This means users, maybe inadvertently losing control of their data because they are not able to make, or aware they have the right to make, granular choices about what processing or sharing they are or aren't willing to consent to. However, this potential 'loss of control' does not appear to be leading to any specific harms.

### Outcomes

Based on the above findings, two options were proposed as 'next steps':

1. Give detailed, bespoke advice and guidance to each app provider based on the specific concerns identified through our engagement, to improve their data protection compliance generally. This approach will likely have a positive impact on all aps within a

provider's portfolio. Consideration would also need to be given to any audit or follow-up action to confirm that action has been taken following our advice.

2. Open formal investigations into each app to address identified technical data protection compliance concerns. This activity would be time consuming, resource intensive and without guarantee of successful outcomes due to the potential risk of lack of cooperation and jurisdictional issues associated with cross border enforcement.

Option 1 was recommended as the most applicable course of action. It was not considered appropriate to take formal investigative action against any of the apps that have engaged with us on this project. Our data compliance concerns were limited to issues of consent and transparency, which can be instead addressed through bespoke advice and guidance, and further reinforced through general ICO guidance to app developers. Our findings have not surfaced any substantive harms to fertility and menstruation app users through this project and it seemed disproportionate to single out this sector for investigative action when the compliance issues are not limited to this sector. However, should there be a future breach, complaint or allegation around these compliance issues, the ICO would be in an informed position when opening an investigation.

The followings outputs were produced in response to our findings:

•	We issued closure letters to the apps that we engaged with, that
	included bespoke advice and guidance on how to address the
	compliance concerns surfaced in their responses

- Our findings were fed into the wider AdTech strategy work given the potential implications of apps more widely.
- We developed and implemented a comms plan to meet the following aims:
  - to reassure users of fertility and period apps by communicating findings and offering advice on data protection rights and assessing the privacy compliance of apps,
  - to remind app developers of their obligations around consent and transparency by signposting relevant guidance and good practice.

# Appendix 1

APP ID	Name of App	Name of Developer	Location
1			