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IN THE MATTER OF

IMPLICATIONS FOR THE RIGHT TO FREEDOM OF THOUGHT AND THE RIGHT TO MENTAL INTEGRITY OF DATA SHARING BY MENTAL HEALTH WEBSITES IN THE UK AND EU MEMBER STATES AS EVIDENCED IN PRIVACY INTERNATIONAL'S REPORT – YOUR MENTAL HEALTH FOR SALE (2019)

OPINION

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Introduction

- 1. This opinion is drafted in the context of a grant from the Digital Freedom Fund for pre-litigation research on the relevance of the right to freedom of thought in potential legal challenges to practices associated with "surveillance capitalism" in Europe. It will focus on the application of the right to freedom of thought and the related right to mental integrity contained in the EU Charter on Fundamental Rights and Freedoms to the fact patterns documented in Privacy International's 2019 report <u>"Your Mental Health for Sale"</u> and the <u>follow up report</u> in 2020 which showed that 97.78% of all mental health web pages analysed in the UK, France and Germany had a third party element with many providing the data to third parties for advertising purposes.
- 2. Privacy International has already brought a <u>complaint</u> to the French Data Protection Authority (CNIL) about breaches of data protection law by the French website Doctissimo.fr arguing that the company:
 - Has no lawful basis for the processing of personal data, as the requirements for valid consent are not met. Consent is Doctissimo's stated basis for processing and the only available legal basis given the nature of the processing involved. Doctissimo also fails to obtain explicit consent in the case of special category personal data;
 - Does not comply with the Data Protection Principles enshrined in GDPR, namely the principles of transparency, fairness, lawfulness, purpose limitation, data minimisation, and integrity and confidentiality;
 - Does not comply with its obligations under Article 25 (Data Protection by Design and by Default) of the GDPR and Article 32 (Security of Processing) of the GDPR;
 - Should be further investigated as to compliance with the rights, obligations and safeguards in GDPR;
 - Does not comply with the law in its use of cookies and other tracking technologies on users' devices.
- 3. This opinion does not duplicate the legal analysis in their submission but instead explores additional legal arguments that may provide alternative or additional legal bases for challenging the type of practices revealed in the Privacy International Report, in particular mental health websites engaging in programmatic advertising, a type of advertising that relies on sharing our personal data with hundreds if not thousands of companies to eventually serve users with targeted ads and mental health websites that offer depression tests sharing users' answers directly with third parties. The sharing and sale of data related to the mental health of individuals is highly sensitive and engages legal questions around data protection and the right to private life. This opinion will explore the additional legal arguments that may be relevant from the perspective of the absolute rights to freedom of thought and to mental integrity. The analysis will focus on the potential for considering the application of these additional EU Charter rights that may assist in the interpretation of European Union law including the GDPR and the ePrivacy Directive. It will also consider how analysis of the European Convention on Human Rights can support interpretation of EU data protection law. The particular questions it will address are



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- a. How could the rights to freedom of thought and/or mental integrity in the EU Charter be relevant to interpretation of EU data protection law in this context?
- b. How is the interpretation of these rights in the EU Charter informed by parallel rights in the ECHR and the ICCPR?
- c. Are there other aspects of EU law that aid in interpretation of the parameters of the rights to freedom of thought and mental integrity in relation to targeted advertising based on data shared from mental health websites?
- 4. This opinion is based on the information provided in the Privacy International reports cited above and focuses on the international law aspects of freedom of thought and mental integrity which may be applicable in any European jurisdiction where such practices are identified. The way in which this could give rise to potential litigation will depend on whether practices are challenged directly or through a regulator and if the website concerned is run by a public body (like the NHS in the UK) or a private company. These arguments are supplementary to more familiar arguments based on the right to protection of personal data and the right to private life such as those set out in Privacy International's complaint to the CNIL.

Applicability of the EU Charter

- 4. Privacy International's report notes that the practices it identifies raise questions as to compliance with EU law, in particular the General Data Protection Regulation (GDPR)¹ and Member State implementing laws, and the ePrivacy Directive. The practices identified are clearly within the scope of EU law and the application of EU law to those practices should be considered in light of the EU Charter (Article 51.1 EU Charter).
- 5. In <u>Case C-414/16 Vera Egenberger v Evangelisches Werk f
 ür Diakonie und Entwicklung e.V.</u> Advocate General Tanchev² explained the ways in which Charter rights should be understood and applied to EU law:

36) [...] I will detail how and why Articles 52(3) and 53 of the Charter are central to the resolution of the legal problems arising in the main proceedings. Article 52(3) of the Charter states that, in so far as rights contained in the Charter correspond to rights guaranteed by the ECHR, the meaning and scope of those rights shall be the same. Article 52(3) adds that this provision 'shall not prevent Union law providing more extensive protection'. The part of Article 53 that is of primary relevance concerns the statement, as interpreted by the Court in its ruling in Melloni, (16) that nothing 'in this Charter shall be interpreted as restricting or adversely affecting human rights and fundamental freedoms as recognised, in their respective fields of application, by Union law and ... the Member State's constitutions'.

¹ REGULATION (EU) 2016/679 OF THE EUROPEAN PARLIAMENT AND OF THE COUNCIL of 27 April 2016 on the protection of natural persons with regard to the processing of personal data and on the free movement of such data, and repealing Directive 95/46/EC (General Data Protection Regulation) (OJ L 119, 4.5.2016, p. 1) (hereafter the GDPR)

² Opinion of 9 November 2017



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- 6. In its judgment in the same case, the CJEU found that "A national court hearing a dispute between two individuals is obliged, where it is not possible for it to interpret the applicable national law in conformity with Article 4(2) of Directive 2000/78, to ensure within its jurisdiction the judicial protection deriving for individuals from Articles 21 and 47 of the Charter of Fundamental Rights of the European Union and to guarantee the full effectiveness of those articles by disapplying if need be any contrary provision of national law."³
- 7. Compliance with relevant provisions of the EU Charter should be a factor in the interpretation and application of EU law to the practices outlined in the Privacy International report across the EU and in jurisdictions where EU law may inform the interpretation of related laws. Any provisions of national law implementing EU laws should be disapplied where they are contrary to EU Charter rights. The provisions of the EU Charter include but are not restricted to Article 7 (Respect for private and family life) and Article 8 (Protection of Personal Data) of the Charter. While Articles 7 and 8 have been regularly relied on in the interpretation of EU data protection law and are the focus of the Privacy International complaint to the French data protection authority (the CNIL) about Doctissimo.fr, the practices outlined in the Privacy International report raise issues under additional Charter rights which could entail even stronger practical protections. This opinion will focus on Article 3 (The Right to Integrity of the Person) and Article 10 (The Right to Freedom of Thought, Conscience and Religion) and their relevance to interpreting the legality of the practices revealed in the Privacy International report in the UK, France and Germany and similar practices in other countries.

Liability for compliance under the GDPR

 Data controllers are responsible for compliance with European data protection legislation. This responsibility is shared between websites which share information and the third parties they share it with. The European Court of Justice found, in its judgment of 29 July 2019 in <u>Case C-40/17 Fashion ID</u> <u>GmbH & Co.KG v Verbraucherzentrale NRW</u> eV that:

> "the operator of a website, such as Fashion ID, that embeds on that website a social plugin causing the browser of a visitor to that website to request content from the provider of that plugin and, to that end, to transmit to that provider the personal data of the visitor can be considered to be a controller, within the meaning of Article 2(d) of Directive 95/46. That liability is, however, limited to the operation or set of operations involving the processing of personal data in respect of which it actually determines the purposes and means, that is to say, the collection and disclosure by transmission of the data at issue."

9. The findings in this case may be applied by analogy to cookies or other similar tracking technologies which allow websites to share information with third parties.⁴ While this case discussed the application of Directive 95/46, the principles apply equally to interpretation of the GDPR. This means that websites engaging in the type of practices highlighted in the Privacy International report are liable along with the

³ Judgment of 17 April 2018

⁴ See also UK Information Commissioner's Office's <u>guidance on the use of cookies and similar technologies</u> regarding the concept of joint-controllership.



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third parties they share data with for any resulting breaches of EU data protection law. The European Data Protection Board adopted Guidelines 07/2020 on the concepts of controller and processor in the GDPR⁵ in September 2020 which provide more guidance as to the relative liability of joint controllers which can provide further clarity on liability in specific cases brought against websites and/or the third parties they share personal data with.

GDPR and EU Charter Rights

10. Recital 4 of the GDPR describes the relationship between the right to protection of personal data and other rights and freedoms as follows:

"The processing of personal data should be designed to serve mankind. ²The right to the protection of personal data is not an absolute right; it must be considered in relation to its function in society and be balanced against other fundamental rights, in accordance with the principle of proportionality. ³This Regulation respects all fundamental rights and observes the freedoms and principles recognised in the Charter as enshrined in the Treaties, in particular the respect for private and family life, home and communications, the protection of personal data, freedom of thought, conscience and religion, freedom of expression and information, freedom to conduct a business, the right to an effective remedy and to a fair trial, and cultural, religious and linguistic diversity."

11. Article 1 of the GDPR on subject-matter and objectives states that:

"2. This Regulation protects fundamental rights and freedoms of natural persons and in particular their right to the protection of personal data."

This would indicate that the regulation is designed to protect all fundamental rights and freedoms contained in the EU Charter, not only the right to the protection of personal data and the related right to private life. Interpretation of the GDPR more broadly should therefore, where relevant, consider the effect of practices within the scope of the GDPR on any fundamental rights and freedoms of natural persons. Where the impact on certain rights or freedoms implies a higher standard of protection, that is the standard that should be applied.

- 12. The Privacy International report highlights issues relating to lawfulness, fairness and transparency in the way mental health websites process the personal data of users. The practices reveal two particular areas of concern in relation to processing:
 - A The sharing of mental health data with third parties; and
 - B The processing of mental health data for the purposes of targeted advertising.
- 13. The GDPR contains the following principles relating to processing of personal data in its Article 5:
 - 1.Personal data shall be:

(a) processed lawfully, fairly and in a transparent manner in relation to the data subject ('lawfulness, fairness and transparency');

⁵ https://edpb.europa.eu/sites/edpb/files/consultation/edpb_guidelines_202007_controllerprocessor_en.pdf



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 (b) collected for specified, explicit and legitimate purposes and not further processed in a manner that is incompatible with those purposes; further processing for archiving purposes in the public interest, scientific or historical research purposes or statistical purposes shall, in accordance with Article 89(1), not be considered to be incompatible with the initial purposes ('purpose limitation');

(f) processed in a manner that ensures appropriate security of the personal data, including protection against unauthorised or unlawful processing and against accidental loss, destruction or damage, using appropriate technical or organisational measures ('integrity and confidentiality').

2. The controller shall be responsible for, and be able to demonstrate compliance with, paragraph 1 ('accountability').

14. The interpretation of lawfulness under Article 5 of the GDPR must take account of the potential for processing to violate not only the explicit provisions of the GDPR, but also the fundamental rights and freedoms set out in the EU Charter. In relation to EU data protection law, the CJEU, in its judgment in Google v Spain noted:

"The Court has already held that the provisions of Directive 95/46, in so far as they govern the processing of personal data liable to infringe fundamental freedoms, in particular the right to privacy, must necessarily be interpreted in the light of fundamental rights, which, according to settled case-law, form an integral part of the general principles of law whose observance the Court ensures and which are now set out in the Charter (see, in particular, Case C-274/99 P Connolly v Commission EU:C:2001:127, paragraph 37, and Österreichischer Rundfunk and Others EU:C:2003:294, paragraph 68)."⁶

While the Court's analysis referred only to Articles 7 and 8 of the Charter in any detail, it is clear that all Charter rights are relevant to the lawfulness of the processing of personal data in EU law.

15. Paragraph 2 of Article 5 makes it clear that it is for the data controller to demonstrate such compliance, not for the individual affected. The Privacy International report reveals practices that raise very serious questions about compliance with EU data protection law and potentially serious violations of the fundamental rights of individuals using mental health websites although the ultimate use of the data and the full scale of the impact on fundamental rights cannot be ascertained. In these circumstances, it is for the joint controllers to demonstrate full compliance of their activities with EU law including respect for the full range of relevant fundamental rights and freedoms set out in the Charter. The joint controllers include both the websites and the third parties that they share personal data with though the

⁶ Judgment of 13 May 2014 in Case C131/12



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establishment of the exact extent of their respective liabilities would require further investigation on a case by case basis.

Article 10 EU Charter – The Right to Freedom of Thought

- 16. The right to freedom of thought and the related right to freedom of expression and information, which includes the right to hold opinions are noted in Recital 4 of the GDPR as having particular relevance in the context of processing of personal data. The right to freedom of thought is guaranteed by EU Charter Article 10 alongside the rights to freedom of conscience and religion. It is closely related to the right to hold opinions protected in the right to freedom of expression and information in Article 11. There is no direct CJEU jurisprudence on the right to freedom of thought as separate from other elements of Article 10 or of the right to hold opinions as protected by Article 11 but, in accordance with Article 52(3) of the Charter, interpretation of the right to freedom of thought must, at a minimum, reflect the right as guaranteed by Article 9 of the European Convention on Human Rights.
- 17. In the absence of jurisprudence on the right to freedom of thought as opposed to the religious aspects of Article 9 or those related to freedom of conscience, some jurisprudence and academic analysis gives an indication of the potential scope of the right. The European Commission of Human Rights has found that, given the "comprehensiveness of the concept of thought", a parent's wish to name their child in a certain way would come within the scope of the right to freedom of thought.⁷ This would indicate a broad scope of protection for all kinds of thought which is reflected in the jurisprudence, guidance and literature on the right to freedom of thought, conscience and religion in the UN framework, notably Article 18 of the UDHR and the ICCPR. The UN Human Rights Committee in General Comment 22 on Article 18 of the ICCPR has said that the right is "profound and far-reaching."⁸ Professor Martin Scheinin has described⁹ freedom of thought, conscience and religion in Article 18 UDHR taken together as protecting the "absolute character of the freedom of an inner state of mind."¹⁰ This would indicate that the scope of 'thought' is potentially broad including things such as emotional and mental states that could be considered as protected by Article 9 ECHR and, by extension, Article 10 of the EU Charter. Academic analysis of the protection of the "forum internum" afforded by the rights to freedom of thought¹¹ and the right to freedom of opinion¹² includes studies of the application of the right to neuroscience¹³ and to mental states in the context of mental health.¹⁴ The kind of thoughts, emotional

⁷ Salonen v Finland (1997) 25 E.H.R.R. 371

⁸ CCPR/C/21/Rev.1/Add.paras 1 and 3. See also GC No 34 on Article 19 para 5

⁹ While mentioned in human rights texts covering Article 9 ECHR and Article 18 UDHR and ICCPR, there is little in-depth analysis.

 ¹⁰ M. Scheinin, "Article 18", in: A. Eide et al. (eds.) UDHR: A Commentary. (Scandinavian University Press, 1992), pp 264-266
 ¹¹ e.g. S. Alegre, <u>"Rethinking Freedom of Thought for the 21st Century</u>" EHRLR 2017

¹² e.g. E. Aswad, "Losing the Freedom to Be Human" Columbia Human Rights Law Review, Vol. 52, 2020

¹³ C. Bublitz, Freedom of Thought in the Age of Neuroscience January 2014 Archiv fur Rechts und Sozialphilosophie 100(1):1-25

¹⁴ F. Beaupert, "Freedom of Opinion and Expression: From the Perspective of Psychosocial Disability and Madness" Laws **2018**, 7, 3; doi:10.3390/laws7010003



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and mental states that are revealed by browsing particular websites related to mental health or filling in questionnaires related to mental states are, therefore, likely to be considered as falling within the scope of protection of the *"forum internum"* under the right to freedom of thought and/or the related right to freedom of opinion.

- 18. Article 9 of the ECHR recognises two separate aspects of the right to freedom of thought an internal aspect (the *"forum internum"*) and an external aspect, the manifestation of thoughts and beliefs. The European Court of Human Rights has recognised that the internal aspect of the right to freedom of thought, conscience and belief is protected absolutely and unconditionally by the ECHR while the right to manifest religion and beliefs is a limited right.¹⁵ Where a practice amounts to an interference with the right to freedom of thought in the *"forum internum"* therefore, there can be no lawful justification for the interference.
- 19. There is very limited and inconsistent jurisprudence on the exact boundaries between the "forum internum" and the manifestation of thoughts and beliefs under Article 9 ECHR¹⁶ and none in relation to thought as opposed to religion, belief or conscience. This right and the related right to freedom of opinion have yet to be the subject of litigation in the context of data protection and the digital sphere. However their relevance has been noted by United Nations Special Rapporteurs flagging the implications of surveillance, data profiling and targeting for the absolute right to freedom in the "forum internum" and highlighting the absolute protection accorded to thoughts, opinions and ideas before they are consciously shared with the outside world.¹⁷ The UN Special Rapporteur on Freedom of Opinion and Expression has pointed to the fact that "[I]ndividuals regularly hold opinions digitally, saving their views and their search and browse histories... In other words, holding opinions in the digital age is not an abstract concept limited to what may be in one's mind."¹⁸ and that "[S]urveillance systems, both targeted and mass, may undermine the right to form an opinion, as the fear of unwilling disclosure of online activity, such as search and browsing, likely deters individuals from accessing information..."¹⁹
- 20. Academic analysis of the practical protections afforded by the right to freedom of thought in Article 9 ECHR indicates three main elements of the right:
 - the right not to reveal one's thoughts;
 - the right not to have one's thoughts manipulated; and
 - the right not to be penalised for one's thoughts²⁰.

¹⁵ (Ivanova v. Bulgaria, § 79; Mockutė v. Lithuania, § 119)

¹⁶ <u>Mawhinney, A</u> 2016, <u>Coercion, oaths and conscience: conceptual confusion in the right to freedom of religion or belief</u>. in F Cranmer, M Hill QC, C Kenny & R Sandberg (eds), *The Confluence of Law and Religion: Interdisciplinary Reflections on the Work of Norman Doe.* Cambridge University Press, pp. 205-218.P. Taylor, *Freedom of Religion: UN and European Human Rights Law and Practice,* Cambridge University Press (2006)

 ¹⁷ See e.g. UN Special Rapporteur on Freedom of Expression: <u>Report on Artificial Intelligence technologies and implications</u> for freedom of expression and the information environment and <u>Research Report on Artistic Freedom of Expression</u>
 ¹⁸ UN Special Rapporteur on Freedom of Expression <u>Report on encryption, anonymity, and the human rights framework</u>
 ¹⁹ ibid

²⁰ B. Vermeulen, "Article 9" in: P. van Dijk/F. van Hoof/A. van Rijn/L. Zwaak (eds.): Theory and Practice



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The practices described in the Privacy International report raise potential issues under all three limbs of the right to freedom of thought. The sharing of data relating to a user's browsing history on mental health websites and their responses to self-assessment questionnaires undermines the right not to reveal one's thoughts. Academic analysis of Article 9 ECHR has noted that:

"In essence, there are unlikely to be many good reasons why the state should need to have specific information abut what an individual believes – but there are undoubtedly many bad ones, especially when one bears in mind the Inquisition and the coercive investigations of modern totalitarian regimes."

Similarly, there are undoubtedly many bad reasons why companies, including digital advertising companies may want to have information on individuals' mental states. If there are good reasons for sharing this data which do not violate a user's right to freedom of thought, the burden is on the websites and the third parties they share personal data with as joint controllers to demonstrate what those reasons are and why they are relevant to the specific circumstances. Based on the evidence from Privacy International's report, good reasons for sharing mental health data are not readily apparent.

21. The sharing of data on mental health to third parties, including advertisers raises serious concerns about the future use of such data and its impact on fundamental rights. In 2019, the Council of Europe's Committee of Ministers issued a Declaration on the Manipulative Capabilities of Algorithmic Processes which recognised that:

"[f]ine grained, sub-conscious and personalised levels of algorithmic persuasion may have significant effects on the cognitive autonomy of individuals and their right to form opinions and take independent decisions."21 In the same declaration, the Council of Ministers recognised that this could "lead to the corrosion of the very foundations of the Council of Europe."

22. Academic analysis has stressed that the significance of the absolute guarantee of inner freedom of thought, conscience and religion:

"implies that one cannot be subjected to a treatment intended to change the process of thinking, that any form of compulsion to express thoughts, to change opinion, or to divulge a religious conviction is prohibited, and that no sanction may be imposed either on the holding of any view whatever or on the change of a religion or conviction: it protects against indoctrination by the State".²²

23. Where information about a person's mental health and state of mind is shared for the purposes of targeted advertising, this could violate the right not to have one's thoughts manipulated that is

of the European Convention on Human Rights, 4th Ed., (Cambridge: Intersentia Press 2006) p.752; D. J. Harris, M. O'Boyle and C. Warbrick, Law of the European Convention on Human Rights, London: Butterworths (1995), at pp. 360–2 ²¹ <u>https://search.coe.int/cm/pages/result_details.aspx?ObjectId=090000168092dd4b</u>

²² P van Dijk/F van Hoof supra, 1998 edition pp 541-2



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protected under Article 10 of the EU Charter and Article 9 of the ECHR. The European Court of Human Rights in the case of Kokkinakis v Greece²³ said that:

"... a distinction has to be made between bearing Christian witness and improper proselytism. The former corresponds to true evangelism, which a report drawn up in 1956 under the auspices of the World Council of Churches describes as an essential mission and a responsibility of every Christian and every Church. The latter represents a corruption or deformation of it. It may, according to the same report, take the form of activities offering material or social advantages with a view to gaining new members for a Church or exerting improper pressure on people in distress or in need; it may even entail the use of violence or brainwashing; more generally, it is not compatible with respect for the freedom of thought, conscience and religion of others."²⁴

- 24. This distinction may be analogous to the sphere of advertising and marketing including online advertising. While all advertising and marketing, like many legitimate activities, is designed to persuade, there is a difference between advertising activities that amount to legitimate persuasion and those that amount to improper manipulation. This distinction is reflected in several pieces of EU legislation such as the Unfair Commercial Practices Directive²⁵ and the Audiovisual Media Services Directive²⁶ that may be considered applicable or analogous to the situation of online advertising and which, in practice, provide a degree of protection for the right to freedom in the *"forum internum."*
- 25. In cases such as those described in the Privacy International report, the use of individual mental health data which may identify vulnerability for the purposes of targeted advertising must fall on the wrong side of the line between legitimate influence and manipulation. In these circumstances, the potential for targeted advertising to manipulate an individual's thoughts or opinions in violation of their right to freedom of thought and/or opinion is not dependent on the individual being identified. Anonymisation of data that still allows for targeted advertising or nudging techniques cannot cure the risk of a violation of the right to freedom of thought through the sharing of personal data from access to mental health websites.

Article 3 EU Charter – The Right to Mental Integrity

²³ application No. 14307/88, Judgment of 25 May 1993

²⁴ Ibid at para 48

 $^{^{\}rm 25}$ DIRECTIVE 2005/29/EC OF THE EUROPEAN PARLIAMENT AND OF THE COUNCIL of 11 May 2005

concerning unfair business-to-consumer commercial practices in the internal market and amending Council Directive 84/450/EEC, Directives 97/7/EC, 98/27/EC and 2002/65/EC of the European Parliament and of the Council and Regulation (EC) No 2006/2004 of the European Parliament and of the Council (Unfair Commercial Practices Directive)

²⁶ Directive (EU) 2018/1808 of the European Parliament and of the Council of 14 November 2018 amending Directive 2010/13/EU on the coordination of certain provisions laid down by law, regulation or administrative action in Member States concerning the provision of audiovisual media services (Audiovisual Media Services Directive) in view of changing market realities <u>https://eur-lex.europa.eu/eli/dir/2018/1808/oj</u>



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26. The right to mental integrity is also relevant to the sharing of data received through websites that are offering services related to mental health for the purposes of targeted advertising. Article 3 of the EU Charter provides the right to integrity of the person in the following terms:

Everyone has the right to respect for his or her physical and mental integrity.
 In the fields of medicine and biology, the following must be respected in particular:

 (a) the free and informed consent of the person concerned, according to the procedures laid down by law;

(b) the prohibition of eugenic practices, in particular those aiming at the selection of persons;
(c) the prohibition on making the human body and its parts as such a source of financial gain;
(d) the prohibition of the reproductive cloning of human beings.

- 27. The right includes both physical and mental integrity. The reference to the field of medicine in paragraph 2 must, logically, be considered to include medicine related to mental health as well as physical health. In the context of websites providing information and assessments related to mental health and data that reveals mental health status, therefore, Article 3 is relevant to an assessment of their practices.
- 28. The Privacy International Report notes that:

"Depression test results should not be shared with third parties

We found that four out of nine depression test websites share test answers and test results with third parties, either as variables or directly. Answers to depression tests and results of depression tests clearly constitute personal data concerning health, as these are shared with third parties together with unique identifiers that are associated with users. In other words, a third party that receives this data could easily tell that, for example, user 274873873 answered yes to the question "have you had trouble getting out of bed?". As noted above, in recognition of the sensitive nature of data relating to health it constitutes special category data under the GDPR.

Article 9(1) of the GDPR defines special category as "personal data revealing racial or ethnic origin, political opinions, religious or philosophical beliefs, or trade union membership, and the processing of genetic data, biometric data for the purpose of uniquely identifying a natural person, **data concerning health** or data concerning natural person's sex life or sexual orientation". As noted above, it prohibits the processing of such data, unless, among others, data subjects have "given explicit consent to the processing of those personal data for one or more specified purposes".

However, from our research none of the four websites that have shared people's test results with third parties have obtained valid consent, let alone explicit consent, for processing and sharing personal data, including special category data. Only the NHS website has a clear banner allowing user to accept or refuse cookies, but it failed to inform users that their answers would be shared and stored on an Adobe server (Adobe Analytics is only mentioned in the privacy policy)." (p.25)

29. Interpretation of Article 9(1) of the GDPR in relation to the sharing of mental health data, in particular detailed information such as depression test results, should take account of Article 3 of the EU Charter. An assessment of what amounts to *"explicit consent to the processing of those personal data for one or more specified purposes"* in the context of mental health data should reflect the requirement for *"free*



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and informed consent" under Article 3. This would seem to be a higher standard than valid consent in relation to personal data in general or even "explicit consent" in relation to other types of sensitive data. It is clear that the practices described in the Privacy International report are not based on consent that could be described as "free and informed" and are unlikely to be compliant with Article 3 of the EU Charter.

- 30. Article 3 explicitly prohibits making the human body and its parts as such a source of financial gain in the fields of medicine and biology. As Article 3 covers both physical and mental integrity, it may be inferred that the same approach would apply to commercial exploitation of an individual's mental states in the context of medicine and biology. If a doctor or counsellor were to use a person's depression or anxiety as a source of financial gain by selling information about their mental state for commercial exploitation, this would clearly be unacceptable and would violate the individual's right to mental integrity. Sharing data about mental states for the purposes of targeted advertising for financial gain from websites that purport to provide support in the context of mental health must be considered as a similarly unacceptable interference with the right to mental integrity.
- 31. In the Joined Cases C 148/13, C 149/13 and C 150/13 (A, B and C) before the CJEU on intrusive questioning and other practices to assess sexual orientation, Advocate General Eleanor Sharpston noted in her Opinion at paragraph 67:

"...Even if an applicant consents to any of the three practices (medical examinations, (71) intrusive questioning, or providing explicit evidence), such consent does not change my analysis. The applicant's consent to a medical test for something (homosexuality) that is not a recognised medical condition (i) cannot remedy a violation of Article 3 of the Charter..."

By analogy, consent to the sharing of mental health data including personal responses to depression tests will not remedy a potential violation of Article 3 of the Charter. Consent in circumstances where the sharing of data undermines a user's personal integrity, including the right to mental integrity, will not make this kind of processing of personal data lawful. As it appears that the websites highlighted in Privacy International's report primarily rely on consent as the lawful basis for the processing of user data, given the clear absence of "free and informed consent" it is unlikely that such processing would be lawful.

Other relevant EU legislation

32. The following pieces of legislation relating to unfair commercial practices and to audiovisual media are also relevant in assessing the lawfulness of processing personal data relating to mental health in circumstances where it may be used for targeted advertising or other commercial practices. They could also form the basis of challenges to the activities of the websites highlighted in the Privacy International report and/or the third parties the data is shared with.



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 The Unfair Commercial Practices Directive27 describes circumstances in which commercial practices must be prohibited as they will be considered as unfair in its Article 5: Article 5

Prohibition of unfair commercial practices

1. Unfair commercial practices shall be prohibited.

2. A commercial practice shall be unfair if:

it is contrary to the requirements of professional diligence, (a)

and

it materially distorts or is likely to materially distort the economic behaviour with regard (b) to the product of the average consumer whom it reaches or to whom it is addressed, or of the average member of the group when a commercial practice is directed to a particular group of consumers.

3. Commercial practices which are likely to materially distort the economic behaviour only of a clearly identifiable group of consumers who are particularly vulnerable to the practice or the underlying product because of their mental or physical infirmity, age or credulity in a way which the trader could reasonably be expected to foresee, shall be assessed from the perspective of the average member of that group. This is without prejudice to the common and legitimate advertising practice of making exaggerated statements or statements which are not meant to be taken literally.

4. In particular, commercial practices shall be unfair which:

(a) are misleading as set out in Articles 6 and 7,

or

(b) are aggressive as set out in Articles 8 and 9.

Article 8

Aggressive commercial practices

A commercial practice shall be regarded as aggressive if, in its factual context, taking account of all its features and circumstances, by harassment, coercion, including the use of physical force, or undue influence, it significantly impairs or is likely to significantly impair the average consumer's freedom of choice or conduct with regard to the product and thereby causes him or is likely to cause him to take a transactional decision that he would not have taken otherwise. Article 9

Use of harassment, coercion and undue influence

In determining whether a commercial practice uses harassment, coercion, including the use of physical force, or undue influence, account shall be taken of:

- its timing, location, nature or persistence; (a)
- (b) ...

²⁷ DIRECTIVE 2005/29/EC OF THE EUROPEAN PARLIAMENT AND OF THE COUNCIL of 11 May 2005

concerning unfair business-to-consumer commercial practices in the internal market and amending Council Directive 84/450/EEC, Directives 97/7/EC, 98/27/EC and 2002/65/EC of the European Parliament and of the Council and Regulation (EC) No 2006/2004 of the European Parliament and of the Council



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(c) the exploitation by the trader of any specific misfortune or circumstance of such gravity as to impair the consumer's judgement, of which the trader is aware, to influence the consumer's decision with regard to the product;

(d) any onerous or disproportionate non-contractual barriers imposed by the trader where a consumer wishes to exercise rights under the contract, including rights to terminate a contract or to switch to another product or another trader;.....

The use of information about the state of a person's mental health that indicates a person is in distress or in need, or is otherwise vulnerable and susceptible to certain types of messaging for the purposes of targeted advertising for financial gain may be considered as an aggressive commercial practice in contravention of the Directive. From the perspective of the right to freedom of thought in Article 10 of the EU Charter, it may also be considered as an improper interference with the "forum internum." If data from mental health websites is being shared for the purposes of profiling and targeted advertising, this is likely to be unlawful under the Unfair Commercial Practices Directive which, in turn undermines the principle of lawfulness required by the GDPR for the processing of personal data.

34. The Audiovisual Media Services Directive²⁸ also makes clear the limitations on permissible commercial communications provided by media service providers including online audiovisual commercial communications:

Article 9

1. Member States shall ensure that audiovisual commercial communications provided by media service providers under their jurisdiction comply with the following requirements:

(a) audiovisual commercial communications shall be readily recognisable as such; surreptitious audiovisual commercial communication shall be prohibited;

- (b) audiovisual commercial communications shall not use subliminal techniques;
- (c) audiovisual commercial communications shall not:

(i) prejudice respect for human dignity;

(ii) include or promote any discrimination based on sex, racial or ethnic origin, nationality, religion or belief, disability, age or sexual orientation;

(iii) encourage behaviour prejudicial to health or safety;

²⁸ Directive (EU) 2018/1808 of the European Parliament and of the Council of 14 November 2018 amending Directive 2010/13/EU on the coordination of certain provisions laid down by law, regulation or administrative action in Member States concerning the provision of audiovisual media services (Audiovisual Media Services Directive) in view of changing market realities <u>https://eur-lex.europa.eu/eli/dir/2018/1808/oj</u>



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(iv) encourage behaviour grossly prejudicial to the protection of the environment;

(d) all forms of audiovisual commercial communications for cigarettes and other tobacco products, as well as for electronic cigarettes and refill containers shall be prohibited;

(e) audiovisual commercial communications for alcoholic beverages shall not be aimed specifically at minors and shall not encourage immoderate consumption of such beverages;

(f) audiovisual commercial communications for medicinal products and medical treatment available only on prescription in the Member State within whose jurisdiction the media service provider falls shall be prohibited;

(g) audiovisual commercial communications shall not cause physical, mental or moral detriment to minors; therefore, they shall not directly exhort minors to buy or hire a product or service by exploiting their inexperience or credulity, directly encourage them to persuade their parents or others to purchase the goods or services being advertised, exploit the special trust minors place in parents, teachers or other persons, or unreasonably show minors in dangerous situations.

35. While the Privacy International report does not detail the ways in which personal data shared by mental health websites is used with specific examples of advertising based on such data, the Audiovisual Media Services Directive give an indication of the types of advertising that would be unlawful Targeted advertising or messaging through audiovisual media channels that is based on personal data gathered from users of mental health websites may be considered as "surreptitious" and prejudicial to the respect for human dignity and should therefore be prohibited. While the Privacy International report does not highlight the situation relating to minors accessing mental health websites, there is no apparent differentiation made between minor or adult users and therefore the provisions relating to the moral and mental detriment of minors may also be relevant. The list in Article 9 provides a degree of practical protection to support the fundamental prohibition on manipulation of the *"forum internum"* guaranteed by the rights to freedom of thought, freedom of opinion and the right to mental integrity in the EU Charter.

Conclusions

- 36. The practices revealed in the Privacy International report <u>"Your Mental Health For Sale"</u> engage EU Charter rights beyond the right to protection of personal data and the right to private life. As data controllers, the liability for any violations of EU law resulting from the sharing of user data is shared between the website and the third parties it shares with as joint controllers. It is for the data controller to demonstrate compliance with EU data protection law whether to the relevant regulator or in the context of a direct legal challenge. Consideration of the lawfulness of these practices should include a broader analysis of EU Charter Rights, in particular, in the context of mental health websites sharing user data, the right to freedom of thought and the right to mental integrity.
- 37. The right to freedom of thought in the *"forum internum"* is absolute. This means that the standard of protection afforded by the right may be higher than that provided by rights like the right to private life



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which allow for proportionate limitations on the right. If the practices revealed in the Privacy International report are found to violate the right to freedom of thought in the *"forum internum"* they could never be justified or compliant with EU law.

- 38. The right to mental integrity includes the requirement of "free and informed consent" in the fields of medicine and biology. The prohibition on using body parts for financial gain in the fields of medicine and biology may also be relevant in terms of the way data on mental health may be used. Websites that purport to give advice and support relating to mental health should be included within the field of medicine for the purposes of applying Article 3 of the Charter.
- 39. The types of practices revealed by the Privacy International, in particular the processing of personal data from mental health websites for the purposes of targeted advertising or other forms of messaging, may also raise questions of legality under other aspects of EU law, in particular the Unfair Commercial Practices Directive and the Audiovisual Media Services Directive. These frameworks provide additional detail to assess the lawfulness of the processing of data for these purposes.

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