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1 December 2018

Re: Developing a Privacy Framework (Docket No. 181101997-8997-01)

Dear Ms. MacFarland,

Access Now thanks the National Institute of Standards and Technology ("NIST") for its work to develop a privacy framework to help "identify, assess, manage, and communicate privacy risks."[1] Earlier this year we warmly welcomed NIST's report on "An Introduction to Privacy Engineering and Risk Management in Federal Systems," and we encouraged private entities to adopt its approach.[2] As such, we are heartened by NIST's "consensus-driven, open, and collaborative process" and optimistic that NIST can help provide practical paths toward the implementation of meaningful privacy protections.

Protecting privacy is vital in the digital age, where data can be used to manipulate, discriminate against, and harm people. NIST has published a request for information ("RFI"), which grants an opportunity to provide feedback on the goals, framing, and path of the agency's process. Our comments provide both general observations about NIST's process to develop the Privacy Framework as well as feedback on specific questions NIST has posed.

About Access Now:

Access Now is an international organization that defends and extends the digital rights of users at risk around the world.[3] By combining innovative policy, user engagement, and direct technical support, we fight for a free and open internet that fosters human rights. As part of this mission we operate a global helpline for users at risk to mitigate specific threats. Additionally, we work directly with lawmakers at national and international forums to ensure policy decisions are focused on users and those most at risk.

Access Now has also provided comments to the U.S. National Telecommunications and Information Administration ("NTIA") on its development of the Administration's approach to data privacy.[4] As the RFI indicates, this process is happening in parallel to NIST's own. We encourage these processes to complement one another and our submissions to both

[1] https://www.federalregister.gov/documents/2018/11/14/2018-24714/developing-a-privacy-framework.
[2] https://www.accessnow.org/new-report-helps-u-s-federal-agencies-protect-privacy-companies-use/.
[3] https://www.accessnow.org/.
[4] https://www.accessnow.org/cms/assets/uploads/2018/11/NTIA-Consumer-Privacy-Comments.pdf.

processes are intended to be mutually-reinforcing. For ease of reference, we also are attaching the full text of that submission here as Appendix A.

In addition, as Appendix B we are attaching "Creating a Data Protection Framework: a Do's and Don'ts Guide for Lawmakers," a report written about our experiences working on and supporting the passage and implementation of the General Data Protection Regulation ("GDPR") of the European Union. Finally, Appendix C contains "A User Guide to Data Protection in the European Union," a practical guide on rights in the GDPR and how they can be exercised. We hope these resources will provide valuable information about international data privacy standards and practices that will be useful in NIST's development of a Privacy Framework.

General Observations

A. NIST's approach must continue to center on the user

In "An Introduction to Privacy Engineering and Risk Management in Federal Systems," NIST observed, "[a]n effective privacy risk model must capture the potential cost of problems to individuals."[5] This was a great victory for user-centric privacy. As we observed at the time:

> *"Focusing on the user seems like common sense, but the norm has been to focus exclusively on the entity collecting data, not the person whose data was being collected. This meant considering the users only by proxy, in the form of legal or reputational costs. That approach has been wholly inadequate for taking into account the wide range of threats that we face when our data are collected and processed, and the damage breaches can cause (such as the emotional impact of having our personal photos revealed to the world)."*[6]

We encourage NIST to commit to carry this principle into the development of the Privacy Framework.

It is important to note, however, that there is no model we are currently aware of to assess individual privacy risks, either on average or specific to a person. Accordingly, more research is necessary in order to determine metrics for evaluating impact before this principle can be properly implemented. NIST should invest in and incentivize this research, which must be expansive and not limited to financial harms. Instead, it must also include emotional, psychological, physiological, human rights, and other impacts that individuals may face on account of a privacy event. It should also include a probe of possibilities for individual and collective remedies, including the options people may have to respond to or mitigate those impacts.

[5] https://nvlpubs.nist.gov/nistpubs/ir/2017/NIST.IR.8062.pdf.
[6] https://www.accessnow.org/new-report-helps-u-s-federal-agencies-protect-privacy-companies-use/.

Finally, when it comes to the assessment, it should also be noted that risk is often wrongly only considered in relation to the volume of data at risk. Entities processing large amount of data shall indeed have stringent security and privacy obligations, however, this does not necessarily mean small data sets or data processing activities are without risks. Beyond volume, risks must also take into account the type of data, including particularly sensitive data types such as health and biometric, and the amount of information it reveals about a single individual.

B. A risk-based approach to privacy must recognize that some risks are too high to mitigate

As noted in the RFI, NIST held an initial workshop on the Privacy Framework in October 2018 in Austin, Texas.[7] At that event, speakers appeared to reach consensus that the goal of the NIST process should be to find ways to mitigate privacy risk, but not to get rid of it.[8] While it may be true, as the speakers agreed, that risk can never be totally eliminated, it is important that the Privacy Framework recognize that some risks are too significant to be properly mitigated and advise that in these cases the activity giving rise to the risk should be forfeited by the entity. NIST should research a method for entities to determine where that threshold exists and identify when a proposed activity reaches it.

Additionally, the principle that the model should assess risks for the individual rather than the entity means that the threshold of acceptable risk should be communicated adequately to the individual, who should be able to exercise a choice about whether to accept that risk, along with steps that can be taken by the individual to mitigate that risk on top of what steps the entity has taken. For choice to be meaningful, alternative solutions shall be provided to individuals who decide that a risk is too high. In today's online environment, individuals encounter many "take it or leave it" approaches whereby they are required to agree to uninformative, complex, or misleading terms and conditions or tracking walls that require consent to tracking in order to use a service. If individuals do not agree to these unilaterally decided conditions, they simply cannot use the service. Such a model fails to both adequately inform the individual and provide meaningful choice. Privacy cannot exist on a "take it or leave it" approach.

A post-hoc example of how this may operate can be evaluated by its absence in the recent data breach at Facebook.[9] In that instance, to its credit, Facebook quickly notified (albeit inadequately) the population of potentially impacted users after the breach was discovered. However, as we noted at the time:

> *"[N]either [Facebook's] notice nor the blog post that it links to gives you any information for figuring out whether you specifically have suffered any damage from the breach. Even if Facebook isn't sure yet what, if any, of an individual's information has been compromised, it might have been helpful to advise people*

[7] https://www.nist.gov/news-events/events/2018/10/kicking-nist-privacy-framework-workshop-1.
[8] https://www.nist.gov/news-events/events/2018/10/kicking-nist-privacy-framework-workshop-1.
[9] https://www.accessnow.org/the-breachbook-chronicles-faq-on-facebooks-latest-privacy-debacle/.

to review the information they have in their accounts. As the old adage says, it's smart to "hope for the best but prepare for the worst." That should be applied here from the perspective of the impacted users."[10]

In the end, no matter what steps a data processing entity may take to mitigate risk, it is the individual who is best placed to understand the extent of a risk and make a decision based on their own context and risk threshold. This is not to say that notification is enough. Notice and choice, as experts have noted at length, is a failed model for protecting privacy.[11] Users must have rights to effectively control the processing of their data. There must be an obligation on entities to adequately protect that data, including to meaningfully limit when and to what extent data can be processed.[12] However, where entities are making choices regarding risk thresholds, informing individuals of the factors behind those choices and allowing them to weigh the risk for their own lives empowers people to make more informed, reasonable decisions for themselves.

Specific Responses

A. Minimum Attributes for a Privacy Framework

Consensus-driven and developed and updated through an open, transparent process - It is too often true that multi-stakeholder processes get captured by the most powerful and well-resourced voices in the room.[13] NIST must ensure to its fullest capability that all voices are given equal footing in the development of the Privacy Framework. NIST should also recognize that even within a single sector, several groups may disagree about form or substance of a given issue, and take steps to ensure that a multitude of voices are heard and highlighted throughout the process and reflected in the document.

Common and accessible language - We applaud NIST for its commitment to accessible language, which we have found lacking in other government processes.[14] We encourage NIST to follow this through by ensuring that complicated concepts or documents on which the foundation is based are summarized or simplified for a general audience. For example, in places where NIST's Cybersecurity Framework is referenced, it would be good to provide detail on the overlap between the two processes so that an individual does not have to become well versed in one project to participate in this one.

Risk-based, outcome-based, voluntary, and non-prescriptive - We encourage that, among the outcomes presented here, NIST include "effectively protects privacy," or

[10] *Id*.
[11] https://epic.org/2016/07/epic-tells-fcc-to-reject-notic.html.
[12] https://www.accessnow.org/data-protection-in-the-united-states-heres-what-we-need-to-protect-the-users/.
[13] *See*, *e.g.*, https://www.eff.org/document/privacy-advocates-statement-ntia-face-recognition-process.
[14] *See, e.g.*, https://www.ntia.doc.gov/files/ntia/access-04202015.pdf at fn 1 ("For purpose of this comment, we refer to the so called "UAS" as drones throughout, and encourage NTIA to do the same throughout its rulemaking process. In order to adequately involve the public as a stakeholder, it is important to use terms that the public understands and finds accessible. Nondescript acronyms will undermine public involvement and bias respondents toward government, companies, and a small number of civil society groups who understand the issue.").

similar language to indicate action at limiting data processing rather than just encouraging research and innovation.

Compatible with or may be paired with other privacy approaches - The Privacy Framework should aim to take into account the benefits of and learn from the flaws of data protection laws around the world, including the GDPR in the European Union, the Brazilian Internet Law,[15] and other current or soon-to-be passed measures with which entities will have to comply.

B. Goals of the Privacy Framework

The RFI identifies three goals of a Privacy Framework:

I. To better understand common privacy challenges in the design, operation, and use of products and services that might be addressed through a voluntary Privacy Framework;
II. to gain a greater awareness about the extent to which organizations are identifying and communicating privacy risk or have incorporated privacy risk management standards, guidelines, and best practices, into their policies and practices; and
III. to specify high-priority gaps for which privacy guidelines, best practices, and new or revised standards are needed and that could be addressed by the Privacy Framework or a related roadmap.

While we find these to be admirable goals, we also find them to be missing important objectives. As with the outcomes identified above, we don't find that any of the goals identified will actually address privacy challenges that impact users today. Additionally, while now is a crucial moment to establish uniform standards around data protection, neither the identified outcomes nor goals align with, complement, or even recognize those from the NTIA process.[16] For example, the NTIA process includes as goals to incentivize privacy research and FTC enforcement. We encourage NIST to harmonize the identified goals and outcomes with those of the NTIA proposal, along with any subsequent changes in response to public comments.

C. Specific Privacy Practices

One in the list of practices or services NIST expresses interest in receiving information is "de-identification." Here, we encourage NIST to exercise care in nuance. While information may be de-identified, in that it can be divorced from a specific direct identifier, databases with even a

[15] https://www.pnm.adv.br/wp-content/uploads/2018/08/Brazilian-General-Data-Protection-Law.pdf; *see also* https://www.accessnow.org/brazil-president-approves-data-protection-bill-but-vetoes-key-accountability-measures .

[16] *See*, https://www.federalregister.gov/documents/2018/09/26/2018-20941/developing-the-administrations-approach-to-consumer-privacy; https://www.federalregister.gov/documents/2018/10/11/2018-22041/developing-the-administrations-approach-to-consumer-privacy (extending deadline for comment).

small number of data points are often at risk of re-identification with trivial ease.[17] Machine learning tools make this process even easier.[18] However, de-identification is not the only way to protect data: in fact it's only one within a spectrum of methods, including anonymization, wherein steps are taken to prevent re-identification.[19] NIST's inquiry should look beyond simply de-identification to include anonymization and aggregation techniques that will better protect data as artificial intelligence tools continue to advance.

Additionally, NIST also lists "enabling user preferences." Several academics have recently explored the extent that user interface and design decisions impact the ability of people to exercise meaningful choice regarding the use or distribution of their data.[20] Recently, a coalition of consumer organisations sent a letter to the Federal Trade Commission calling for an investigation into tech giants deceptive design practices that steer users to "agree" to privacy-invasive default settings.[21] Any exploration of the existence of user preferences should also include an element of analyzing the design choices that underlie those preferences, including efficacy, intuitiveness, and degrees of nuance, including within the nuance of differing contexts of use.

Conclusion

We appreciate NIST's engagement with the privacy community. We look forward to continuing to work with your office throughout this process.

Thank you,

Amie Stepanovich
U.S. Policy Manager
Access Now

Estelle Massé
Global Data Protection Lead
Access Now

[17] *See, e.g.*, https://www.zdnet.com/article/re-identification-possible-with-australian-de-identified-medicare-and-pbs-open-data.
[18] *See, e.g.*, https://journals.openedition.org/factsreports/4494.
[19] For the spectrum of ways to protect data, *see* https://fpf.org/2016/04/25/a-visual-guide-to-practical-data-de-identification/.
[20] *See, e.g.*, http://www.hup.harvard.edu/catalog.php?isbn=9780674976009.
[21] *See*, https://thepublicvoice.org/wp-content/uploads/2018/06/FTC-letter-Deceived-by-Design.pdf.

Appendix A

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Attn: Privacy RFC
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November 9, 2018

Re: Developing the Administration's Approach to Consumer Privacy (Docket No. 180821780-8780-01)

Mr. Hall,

Thank you for the opportunity to comment on the National Telecommunications & Information Administration's (NTIA) proposal on data privacy.[1] We welcome the leadership demonstrated by NTIA in this proposal. However, there is still room for improvement. Below we provide general comments on the structure and framing that we believe will better serve NTIA's goals and intent. We then respond to specific questions posed by NTIA.

About Access Now:

Access Now is an international organization that defends and extends the digital rights of users at risk around the world.[2] By combining innovative policy, user engagement, and direct technical support, we fight for a free and open internet that fosters human rights. As part of this mission we operate a global helpline for users at risk to mitigate specific threats. Additionally, we work directly with lawmakers at national and international forums to ensure policy decisions are focused on users and those most at risk.

General Observations

A. Privacy is about more than consumers

The thrust of the NTIA's proposal specifies the need "to advance consumer privacy." However, in the internet age privacy protections must extend far beyond consumers. Many of the tools and services used by people today are not goods in the traditional sense - people do not pay

[1] https://www.federalregister.gov/documents/2018/09/26/2018-20941/developing-the-administrations-approach-to-consumer-privacy; *See also* https://www.federalregister.gov/documents/2018/10/11/2018-22041/developing-the-administrations-approach-to-consumer-privacy (extending deadline for comment).
[2] https://www.accessnow.org/.

to use them and they do not receive a tangible product. However, this does not mean that there are not significant privacy implications.

For example, users' social media services are probably not "consumers" within the traditional definition, but these services should undoubtedly be subject to any data privacy rules or regulations. Further, while a person may choose to share a piece of information, taken in aggregate millions of data points creates privacy implications at the societal level. Even more troubling online is the passive collection of information from entities like data brokers with whom people may never interact with at all. In fact, these companies may maintain and sell comprehensive data profiles on people who have never heard their name or know they exist. For these reasons, focusing solely on "consumers" is both short sighted and potential harmful to this process. We recommend that the Administration instead focus on the risks to and rights of all people in the United States.

B. Trustworthiness - not trust - should drive data privacy in the United States

NTIA's proposal states, "[u]sers must therefore trust that organizations will respect their interests, understand what is happening with their personal data, and decide whether they are comfortable with this exchange." Counter-intuitively, this framing puts the obligation to act to ensure data privacy on people instead of on the companies themselves. However, rather than people needing to blindly offer trust to companies, it is the companies that must demonstrate that they are worth of receiving and processing user data. It is also the responsibility of companies to provide people with sufficient information in a manner that facilitates their understanding of the scope and purpose of that processing.

As the proposal notes, many Americans have refrained from engaging in important online activities, including economic and civic activities.[3] Since this study, the scope and scale of privacy and security incidents have only increased, affecting billions of users of some of the largest companies in the world, from Facebook to Equifax. No amount of trust would have mitigated the harm caused by these incidents, and preventing future breaches requires affirmative efforts from and changes in behaviour from companies.

These are more than pedantic observations. Several of the NTIA's goals are only served if people are served by a data privacy framework, not obligated to it. At the moment, companies are the only entities in a position to take steps to understand the full scope of their data processing, including the third parties who they transmit data to and the various ways they use that data to make decisions about people. A framework that goes beyond checkboxes and compliance mechanisms must respect this reality to drive companies to act in a way that respects and responds to the needs of the people whose data they are using.

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3 https://www.ntia.doc.gov/blog/2016/lack-trust-internet-privacy-and-security-may-deter-economic-and-other-online-activities

C. A user-centric approach requires that risk is centered on the user

The self-identified "heart" of the NTIA proposal is "risk-based flexibility." While we emphasize the importance of affirmative rights and obligations, we believe it is important for entities that process data to understand and mitigate risk whenever possible.[4] However, there are many entities to which risk can be assessed - risk to the data processor, risk to the general public, or risk to the individual person, to name only a few.

Last year, the U.S. National Institute for Standards and Technologies (NIST) published, "an Introduction to Privacy Engineering and Risk Management in Federal Systems."[5] A central and vital tenet of that report was the observation that, "[a]n effective privacy risk model must capture the potential cost of problems to individuals."[6] In order to ensure that the proposal stays "user centric," NTIA should follow this model and ensure that the risk management element of the proposal refers specifically and clearly to the risk of the person to whom the data pertains.

Focusing on the person seems like common sense, but the norm has been to focus exclusively on the entity collecting data, not the person whose data was being collected. This meant considering the users only by proxy, in the form of legal or reputational costs. That approach has been wholly inadequate for taking into account the wide range of threats created by data processing, and the harm that may be caused by failure to protect that data (such as the emotional impact of having our personal photos revealed to the world).

D. State-level legislation must be allowed to help drive innovation

Broad federal preemption of data privacy laws will stunt innovation and undermine the protection of data. The NTIA proposal claims "fragmentation naturally disincentivizes innovation by increasing the regulatory costs for products that require scale." While this may be superficially true, it fails to consider how privacy itself is a driver of innovation, and state laws are drivers of privacy, as we have recently seen with the recently passed California law facilitating national conversations.

States are more nimble than the federal government - either the executive or legislative branches. State legislators can respond more efficiently and effectively to rapid developments in technology. By keeping preemption out of the proposal, or strictly limiting its scope, NTIA will leave room for states to identify, analyze, and where necessary, respond to emerging gaps in privacy law in the future, which may once again prompt federal action.

At the same time it is not assured, as the NTIA proposal implies, that the absence of full federal preemption will lead to meaningful fragmentation. Today, we see several states considering

[4] See https://www.accessnow.org/data-protection-in-the-united-states-heres-what-we-need-to-protect-the-users/.
[5] https://nvlpubs.nist.gov/nistpubs/ir/2017/NIST.IR.8062.pdf.
[6] *Id*. *See also* https://www.accessnow.org/new-report-helps-u-s-federal-agencies-protect-privacy-companies-use/.

privacy laws in direct response to the absence of a federal standard. However, a strong national law could remove the pressure of the total absence of protections moving lawmakers to act unless future shifts in technology or business practice require it.

Responses to Request for Comment

A. Privacy Outcomes

NTIA has asked for feedback on the thoroughness and clarity of the privacy outcomes identified in the proposal, as well as any risks that the identified outcomes may pose.

Transparency - To realize transparency as an outcome, the description must expressly extend to transparency into how organizations disclose information to third parties. Any entity that processes data should not only ensure that people easily understand how they process data, but specifically identify any entity that data may be disclosed to, what data may be disclosed, and the nature of the relationship between the entity and the third party. This information shall be proactively communicated to people, who should also be notified of any updates in these practices.

Control - Along with transparency, meaningful user controls to opt into non-necessary data collection and data disclosure practices can empower people. Control should include considerations of social context, including how people interact, or don't interact, with the relevant entity. Further, the proposal would benefit from a more thorough description of what practices may be considered "reasonable," particularly in regard to entities with no first-person relationship to the person about whom data is processed.

Reasonable Minimization - Noting our recommendation that the risk assessed is risk to the person directly, the level of "acceptable risk" determined by the data processor should be disclosed to the person to whom the data relates in a manner that aids understanding of their exposure. Access controls should also be considered as mechanisms to reduce risk.

Security - All data processed by any entity should be secured.

Access and Correction - It is necessary that the proposal include greater detail about what is meant by "qualified access" to personal data. Further, this right should extend not only to the data a person "provides," but to any data pertaining to that person, with exceptions to protect the exercise of human rights. Further, more work should be done to understand what impact deletion rights will have on AI training sets and how to preserve those rights while preserving the ability to use AI tools in a respectful manner.

Risk Management - Any strategy that prioritizes risk mitigation must recognize that there will always be some risk that cannot be mitigated and provide for cessation of any processing that creates risk in excess of what can be controlled.

Accountability - An effective accountability structure must provide a pathway to a private right of action for people who have suffered harm from direct action of a data processor.

Processing and Purpose Limitations - We urge NTIA to include new outcomes for limitations on the bases and purpose for processing data. Data processing should be limited to specific bases, enumerated by law. These may include for example, meaningful, opt-in consent, execution of a contract, or as otherwise necessary under law. The bases for processing data should be identified by the entity, along with the purpose for which that processing is conducted. Acceptable purposes should be prevented from including any use that is discriminatory or has an overly vague description. These purpose limitations must contemplate the most harmful business models - such as those used by data brokers. Without these limitations, the other outcomes fail to provide necessary levels of protection.

B. Proposed High-Level Goals

NTIA has asked for feedback on the thoroughness and clarity of the proposed high-level goals identified in the proposal, as well as any risks that the identified outcomes may pose.

Harmonize the federal landscape; Legal clarity while maintaining the flexibility to innovate - As discussed above, an approach that prohibits state action on privacy governance may stunt privacy innovation and harm users. Further, the identified goal of a "flexible" approach is best realized by providing space for state action in the future. We recommend NTIA prioritize a strong privacy framework over preemption.

Comprehensive application; Scalability - NTIA is correct that protections must apply to all private sector organizations. A truly comprehensive approach should also apply to government and public interest entities. Further, this proposal must extend to all organizations that process data, including third-party vendors, who must be held to the same standards as any other data processor, with few potential exceptions (such as for employee data for small entities).

Employ a risk and outcome-based approach; FTC enforcement - While a risk-based approach may allow for flexibility, such an approach needs to be accompanied by strong penalty provisions as well as agency guidance in the form of interpretive regulations. Without these elements this approach is rife for misuse and abuse. This can be seen in a historic analysis of the European data protection model. Many of the protections in the General Data Protection Regulation (GDPR) are nearly identical to

those in the Data Protection Directive (DPD) that preceded it in 1995. However, companies frequently bypassed or outright ignored the DPD's requirements due to the weak penalties that it carried for non-compliance, as observed in how many changes entities started to implement when GDPR came into force. We strongly encourage NTIA to make strong penalties and regulations a integral part of their proposal.

Interoperability - The most effective method of ensuring international operability is to learn from the approaches of other entities and ensure that the protections contained in a U.S. approach are at least as strong, if not moreso. This will not only reduce inefficiencies for data processors needing to comply with multiple legal regimes, but help create certainty for data flows between jurisdictions.

Incentivize Privacy Research - In order to actualize the NTIA's stated goal of "more research into, and development of, products and services that improve privacy protections," we highly recommend pursuit of a program that preferences government procurement of products and services from companies that utilize business methods that are not built or supplemented by personal data or data-driven advertising. Grant programs could also be created that fund entities who are investing in privacy-protective business models and practices or approaches that facilitate interoperability. These programs could be funded through penalties levied on entities who fail to comply with the proposed standards. Government entities can also help by demonstrating a commitment to privacy and security themselves, including committing to protecting and facilitating more robust digital security means and methods and exploring best practices for implementing these provisions in certain sectors, such as the internet of things.

C. Next Steps and Measures

Ultimately, a statutory solution is necessary for ensuring meaningful protection for personal data. However, some measures, like the grant program discussed above, can be adopted by the Administration immediately and have an important impact on the data economy. Further discussions may be helpful in determining the full scope of the proposal, but such discussions need to ensure that representatives across various stakeholder groups are on equal footing to the greatest extent practicable, else corporate interests take over the conversation.

D. Definitions

NTIA's proposal would greatly benefit from inclusion of definitions for various terms, including risk, "reasonable," personal information, and sensitive information, though we recommend that any personal information be treated as sensitive information to prevent an unnecessarily narrow approach to protections. We have provided suggestions for some of these terms throughout this document.

E. Federal Trade Commission Authority

If the Federal Trade Commission is intended to act as the primary regulator for privacy protections, it must be given significantly greater resources and authority to carry out its extended mission.

F./G. International Trade; United States Leadership

Discussions on standards of data protection should be kept separate from trade talks and only included in agreement(s) and arrangement devoted exclusively to transfers of personal data, negotiated by experts in that policy area. By nature, trade policies tend to consider legislations protecting users as a barrier to trade. This creates an inherent push for a lowering of standards to the detriment of rights and the interests of people. A lowering of standards would undermine trust in the digital economy as privacy and data protection laws contribute to the free flow of data globally by ensuring a high level of protection for the information shared and contributing to the security of the infrastructure. Accordingly, we urge NTIA to specify that international trade negotiations or debates at the World Trade Organisation are not a forum to discuss measures for the protection of privacy nor an adequate place were to establish new standards.

Conclusion

We appreciate the NTIA's engagement with the privacy community and trust this feedback will assist the agency in refining and improving its current proposal. We look forward to continuing to work with your office to promote strong data privacy standards.

Thank you,

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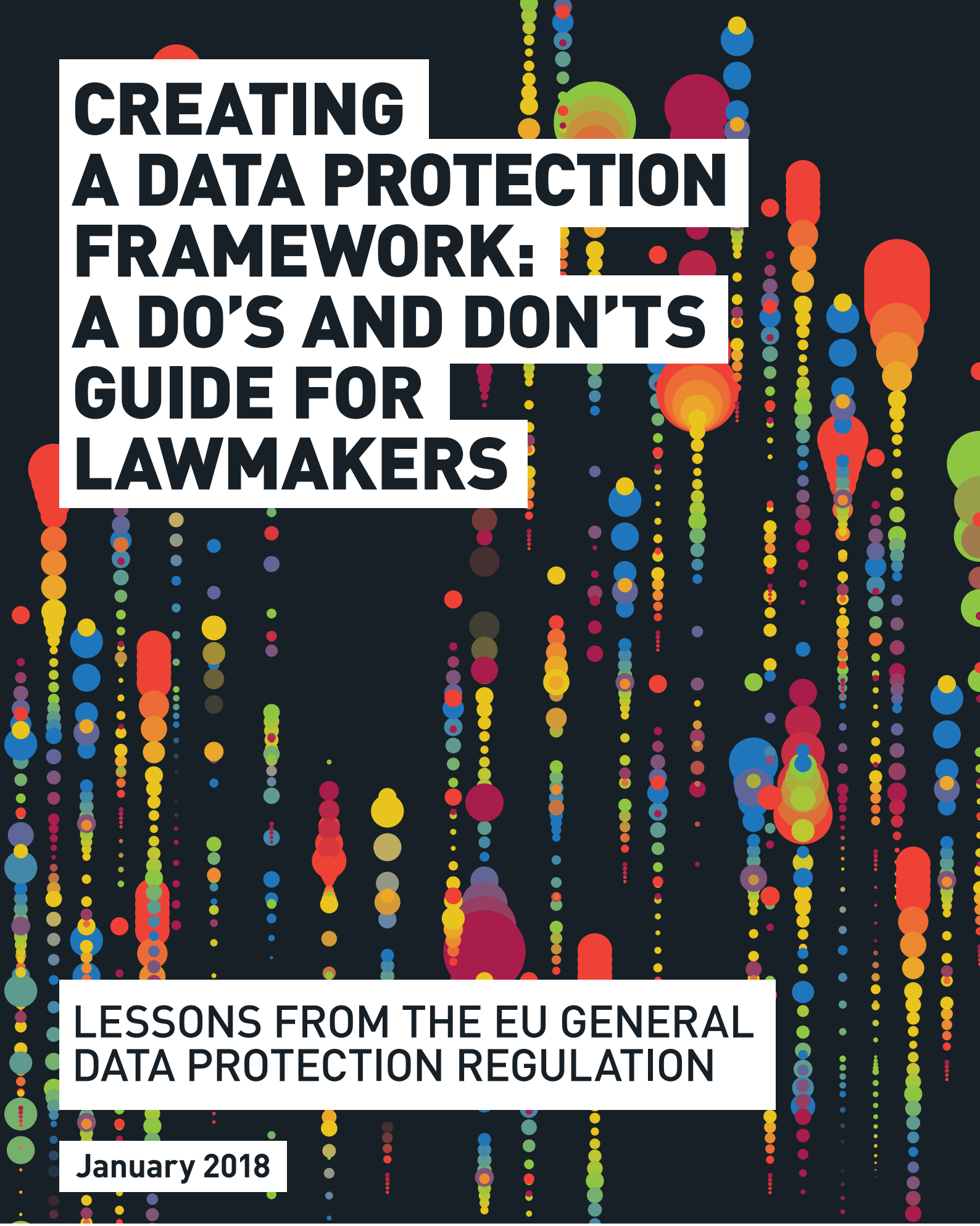
Appendix B



CREATING A DATA PROTECTION FRAMEWORK: A DO'S AND DON'TS GUIDE FOR LAWMAKERS

LESSONS FROM THE EU GENERAL DATA PROTECTION REGULATION

January 2018

accessnow

accessnow.org

Access Now defends and extends the digital rights of users at risk around the world. By combining direct technical support, comprehensive policy engagement, global advocacy, grassroots grantmaking, and convenings such as RightsCon, we fight for human rights in the digital age.

This paper is an Access Now publication.

For more information, please visit: **https://www.accessnow.org,** or contact: **Estelle Masse** | Senior Policy Analyst | **estelle@accesnow.org**

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INTRODUCTION

Access Now presents *Creating a Data Protection Framework: A Do's and Don'ts Guide for Lawmakers - Lessons from the EU General Data Protection Regulation to contribute to the global discourse on data protection*. The paper particularly reflects on the European Union's approach to the debate and the level of protection for personal data around the world.

The General Data Protection Regulation (GDPR) of the European Union is a positive framework for users' protection and will help users take back the control of their personal information. While the law is currently being implemented, it is already inspiring governments around the world to upgrade or develop data protection legislation, which brings massive opportunities. There are important lessons to be learned from the negotiations of the GDPR, many positive and some negative.[1] From our experience, we have created a list of do's and don'ts that lawmakers should consider when developing a data protection framework.

BACKGROUND

Have you ever filed taxes or made a phone call? Do you own a smartphone? Have you ever used the internet? Do you have a social media account or wear a fitness tracker? If the answer is yes to any of these questions, it means that you have been sharing personal information, either online or off, with private or public entities, including some that you may never have heard of. Sharing data is a regular practice that is becoming increasingly ubiquitous as society moves online. Sharing data does not only bring users benefits, but is often also necessary to fulfill administrative duties or engage with today's society. But this is not without risk. Your personal information reveals a lot about you, your thoughts, and your life, which is why it needs to be protected.

The right to protection of personal data is very closely interconnected to, but distinct from, the right to privacy.

More than 160 countries refer to the right privacy in their constitutions, but the understanding of what "privacy" means varies from one country to another based on history, culture, or philosophical influences.[2] This explains why the way to protect privacy might differ from one country to another even if many legal traditions center the protection of privacy on the right to respect for private and family life, home, and correspondence. Data protection, on the other hand, is not always considered as a right in itself. The 28 member states of the European Union are an exception, as they have recognised data protection as a fundamental right in the 2001 EU Charter.[3] However, the protection of personal data is of paramount importance in our

[1] Access Now, General Data Protection Regulation – what tidings do ye bring? https://www.accessnow.org/general-data-protection-regulation-what-tidings-do-ye-bring/
[2] See results provided by the Constitute Project https://www.constituteproject.org/search?lang=en&key=privacy
[3] See Article 8 of the EU Charter of Fundamental Rights, 2001. http://www.europarl.europa.eu/charter/pdf/text_en.pdf

increasingly digital society. It is often recognised through binding frameworks at the national, regional, and international level, and in many places where it is not yet codified, lawmakers are in the process of doing so. We believe this should happen as quickly as possible.

Protecting personal data, or personally identifiable information (PII), means establishing clear rules that any entity that processes your information must follow. This is not a new concept, as data protection laws have been in place in many countries around the world for more than 40 years, but these laws are becoming increasingly important as people are sharing more data and companies' data collection and use skyrockets. The first data protection law was passed in 1970 by the German federal state of Hesse.[4] A few years later, the US developed the "fair information practices" that have influenced modern data protection laws, even though the US has never followed up with a codified legal framework for data protection at the federal level, instead adopting sector-specific laws.[5] Then came the first country-wide laws protecting personal data, in Sweden, Germany, and France, before international organisations such as the Council of Europe adopted international frameworks. The Council of Europe Convention for the protection of individuals with regard to automatic processing of personal data — also known as Convention 108 — was adopted in 1980 and became open for signature in 1981.[6] In 1980, the Organisation for Economic Cooperation and Development (OECD) also developed its privacy guidelines.[7] Since its adoption, the Convention 108 has been ratified by all 47 member countries of the Council of Europe, and by Mauritius, Senegal, Uruguay, and, most recently, in 2017 by Tunisia.[8] The Convention 108 had a pivotal role in the adoption of the first Europe-wide data protection law in 1995.[9] Today, hundreds of countries around the world have adopted general or sectoral data protection laws.[10]

In addition to the frameworks in place, there are countries currently considering data protection legislation: Tunisia, India, Japan, South Korea, Brazil, and Argentina, to name but a few.[11] For some of these countries, it would be their first data protection law. Access Now has worked on data protection legislation across the world since 2009, and in particular, on the EU reform that led to the adoption of the General Data Protection Regulation.[12] The EU and its member states have a long data protection tradition and it is often considered a standard-setter in this area, which means that many countries are interested in replicating the GDPR in their own jurisdictions. There are important lessons to be learned from the negotiations of the GDPR, many positive and some negative. From our experience, we have created a list of do's and don'ts that lawmakers around the world should consider when developing a data protection framework.

[4] Hessische Datenschutzgesetz,Original version dated from 7 October 1970. (GVBl. I S. 625).
[5] See EPIC, the code of fair information practices. https://epic.org/privacy/consumer/code_fair_info.html
[6] Council of Europe, Convention for the protection of individuals with regard to automatic processing of personal data, 1981. http://www.coe.int/web/conventions/full-list/-/conventions/treaty/108
[7] See Privacy International, Data Protection. https://www.privacyinternational.org/node/44
[8] Access Now, Tunisia ratifies Convention 108 and affirms commitment to the protection of personal data https://www.accessnow.org/tunisia-ratifies-convention-108-affirms-commitment-protection-personal-data/
[9] Peter Hustinx, EU Data Protection Law: The Review of Directive 95/46/EC and the Proposed General Data Protection Regulation, 2015. https://edps.europa.eu/sites/edp/files/publication/14-09-15_article_eui_en.pdf
[10] See Privacy International, Data Protection. https://www.privacyinternational.org/node/44
[11] Tunisia national authority for the protection of personal data. Projet de loi relative à la protection des données personnelles, 2017. http://www.inpdp.nat.tn/Projet_PDP_2017.pdf
[12] European Union, Regulation 2016/679/EU 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) http://eur-lex.europa.eu/legal-content/EN/TXT/?uri=CELEX%3A32016R0679

DO'S

Below you will find 10 recommendations for policymakers to follow when developing a data protection law. These 10 steps are individually and collectively necessary to ensure open negotiations and the adoption a user-centric framework.

1 ENSURE TRANSPARENT, INCLUSIVE NEGOTIATIONS

Governments and decision makers must ensure that negotiations of data protection frameworks are conducted in an open, transparent, and inclusive manner. This means conducting public consultations and expert roundtables, publishing negotiating texts and allowing comments from all interested parties with reasonable deadlines, and providing feedback on received comments. In all stages, meaningful participation from civil society groups must be ensured, and all meetings of decision makers with industry, NGOs, and consumer groups must be made public in an easily accessible registry. Maximum transparency around lobbying should accompany the process. Due weight should be given to input from civil society, to redress the inevitable imbalance in number of voices compared with industry.

Experience from the GDPR negotiations

The GDPR negotiations were conducted in accordance with the EU legislative process. This process is fairly transparent and generally ensured the publication of draft proposals, opinions, reports, amendments, and legal opinions of all EU institutions on any piece of legislation being discussed. Some improvements can however be made to this legislative process. First, there should be more accountability in the earliest drafting stage of legislation. Through a FOIA request, Access Now has for instance obtained an email revealing how the Home Affairs department of the European Commission (DG Home) had been working alongside the US administration during the early stages of the privacy reform effort.[13] In addition, the trilogue — the final stage of the negotiations between all EU institutions — is notoriously opaque. Access Now has joined efforts led by European Digital Rights (EDRi) in calling for reforms of the process for years.[14] Because of the lack of transparency during that stage, the public is kept in the dark at the most crucial point in the negotiations; that is, when lawmakers come together to agree on a final compromise text that will become binding after the EU institutions rubber-stamp it.

External stakeholders seeking to influence negotiations should also abide by principles of transparency and accountability. The GDPR negotiations were subjected to an unprecedented lobbying effort during which industry representatives aimed to weaken existing data protection standards and to prevent proposals from strengthening users' rights. The influence of certain industries and foreign companies became visible as lawmakers copied and pasted amendment proposals from lobbying proposals.[15] In that instance, advocacy groups were able to help the public compare the language proposed by lobbyists to the text proposed by lawmakers.[16] This process allowed the public to comment meaningfully on these proposals and helped fight influence via secret backroom dealings. Proposing amendments is not necessarily a shady activity, but it must be done in a transparent manner. People must know where these proposals are coming from and lobbyists should always indicate their affiliation on their proposals and make them available to the public.

[13] Access Now, Big brother's little helper inside the European Commission https://www.accessnow.org/big-brothers-little-helper-inside-the-european-commission/
[14] Access Now, EU "trilogues" consultation: A foot in the door for transparency https://www.accessnow.org/eu-trialogues-consultation-foot-door-transparency/
[15] Access Now, Privacy under siege: Unprecedented lobby efforts against the Regulation are revealed https://www.accessnow.org/privacy-under-siege-unprecedented-lobby-efforts-against-the-regulation-are/
[16] See LobbyPlag initiative http://lobbyplag.eu/compare/overview

2 DEFINE AND INCLUDE A LIST OF BINDING DATA PROTECTION PRINCIPLES IN THE LAW

Any framework aiming to protect personal information must include a clear definition of personal and sensitive data. The level of protection should correspond with the sensitivity of each category of data. Sensitive data should be defined to include genetic and biometric data, as well as communications content and metadata, as this information reveals particularly sensitive personal traits. This means that a data protection framework can also include specific measures for the protection of data exchanged during communications and related privacy provisions to guarantee the confidentiality of communications.

Together with clear definitions, the eight following principles are at the core of data protection frameworks.[17] Put together, these interconnected principles lay down the necessary measures that any data protection framework which seeks to effectively protect users' rights should include. The effective codification of these principles requires the development of a set of users' rights, legal basis for data processing, data security measures, oversight mechanisms, obligations for entities processing data, and of measures enabling the transfer of data to third countries.

1. **Fairness and lawfulness:** Personal data shall be processed fairly and lawfully which means that information should be processed on a clear legal basis, for a lawful purpose, and in a fair and transparent manner so that users are adequately informed about how their data will be collected, used, or stored, and by whom.

2. **Purpose limitation:** Personal data shall be collected and processed only for a specified and lawful purpose. This purpose shall be specific, explicit, and limited in time. Data shall not be further processed in any manner incompatible with that purpose.

3. **Data minimisation:** Personal data collected and used shall be limited to what is adequate, relevant, and not excessive in relation to a specific and defined purpose.

4. **Accuracy:** Personal data shall be accurate and, where necessary, kept up to date. Users shall have the right to erase, rectify, and correct their personal information.

5. **Retention limitation:** Personal data processed for any purpose shall not be kept for longer than is necessary.

6. **Users' rights:** Personal data shall be processed in accordance with the rights of users such as the right to access or right to erasure (See point 4).

7. **Integrity and confidentiality:** Personal data shall be processed in a manner that ensures state-of-the-art security of the data, including protection against unauthorised or unlawful processing and against accidental loss, destruction or damage, using appropriate technical or organisational measures.

8. **Adequacy:** Personal data shall not be transferred to a third country or territory, unless that country or territory ensures an adequate level of protection for the rights and freedoms of users in relation to the processing of personal data. Data protection frameworks shall provide for mechanisms enabling the free flow of data between countries while safeguarding a high level of data protection.

Experience from the GDPR negotiations

The eight data protection principles come largely from international standards, in particular the Convention 108 and the OECD guidelines.[18] These data protection principles are considered "as minimum standards" for the protection of fundamental rights by countries that have ratified international data protection frameworks. These principles should be the basis of any data protection framework and are present in a large number of data protection laws around the world, from the EU Data Protection Directive from 1995, the GDPR, and most data protection laws that are in place in Latin America.

[17] See UK Information Commissioner's Office, Data Protection Principles https://ico.org.uk/for-organisations/guide-to-data-protection/data-protection-principles/
[18] Organisation for Economic Cooperation and Development, September 1980. Guidelines governing the protection of privacy and transborder flows of personal data. https://habeasdatacolombia.uniandes.edu.co/wp-content/uploads/OECD_Privacy_Guidelines_1980.pdf

3 DEFINE LEGAL BASIS AUTHORISING DATA TO BE PROCESSED

Any data protection law must clearly define the legal basis under which users' personal data can be processed. Any entity, public or private, seeking to process personal data must abide by at least one of the legal bases provided for in the law. These usually include the execution of a contract, compliance with a legal obligation, and a user's consent.

Consent shall be defined as an active, informed, and explicit request from the user. It must be freely given and the user must have the capacity to withdraw consent at any time. This means, for instance, that pre-ticked boxes would not qualify as valid consent. In addition, companies cannot deny a user access to a service for refusing to share more data than strictly necessary for the functionality thereof. Otherwise, consent would not be freely given.

Experience from the GDPR negotiations

The GDPR allows for six bases for processing personal data from contract to consent. [19] The definition of consent was strengthened and clarified during the negotiations compared to the definition provided for in its predecessor, Directive 95/46. The GDPR indicates that consent must be "a clear affirmative act establishing a freely given, specific, informed, and unambiguous indication" of the user. However, the GDPR also authorises the processing of data for so-called "legitimate interest" purposes defined by the entity using the information. This provision greatly limits users' control over their personal information as they are often unaware of any data collection or processing when entities rely on legitimate interest (see more on legitimate interest in point two of the "Don'ts" section).

4 INCLUDE A LIST OF BINDING USERS' RIGHTS IN THE LAW

Protecting users' data protection and guaranteeing their control over their personal information requires establishing a series of binding rights to exercise:

1. **Right to access** enables users to obtain confirmation from services and companies as to whether personal data concerning them have been collected and are being processed. If that is the case, users shall have access to the data, the purpose for the processing, by whom it was processed, and more.
2. **Right to object** enables users to say "no" to the processing of their personal information, when they have not given their consent to the processing of their data nor signed a contract. This right to object applies to automated decision-making mechanisms, including profiling, as users have the right not to be subjected to the use of these techniques.
3. **Right to erasure** allows users to request the deletion of all personal data related to them when they leave a service or application.
4. **Right to rectification** allows users to request the modification of inaccurate information about them.
5. **Right to information** ensures that users receive clear and understandable information from entities processing their personal data, whether these entities have collected this information directly or received it through third parties. All the information provided to the user shall be provided in concise, intelligible, and easily accessible form, using clear and plain language. This information shall include details about data being processed, the purpose of this processing, and the length of storage, if applicable. The entities shall provide their contact details and an email address to allow users to contact them in case there are issues.
6. **Right to explanation** empowers users to obtain information about the logic involved in any automatic personal data processing and the consequences of such processing. This right is crucial to bring accountability and transparency in the use of algorithms to make decisions that impact users' lives.
7. **Right to portability** enables users to move certain personal data they have provided from one platform to another offering similar services. To facilitate this process, interoperability between services shall be encouraged.

[19] See Article 6. European Union, Regulation 2016/679/EU 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) http://eur-lex.europa.eu/legal-content/EN/TXT/?uri=CELEX%3A32016R0679

Although this list is not exhaustive, these rights must be provided for by law, and not left to the discretion of entities using the data. Users shall be able to exercise any of these rights free of charge.

Experience from the GDPR negotiations

The GDPR provides users with all mentioned rights, free of charge. The provisions enshrining those rights set detailed obligations on entities processing data to implement, provide for, protect, and respect these rights.[20]

The GDPR is an important step in ensuring that users can freely exercise their right to data protection. However, to ensure that all measures will be effective, there should be further effort to raise awareness about the existence of the law and its content. Governments, public authorities, companies, and NGOs should work jointly to achieve that goal.

Finally, the exercise of certain rights such as the right to portability and the right to explanation are particularly relevant in the era of Big Data and artificial intelligence. However, the full realisation of these rights will not take place without the cooperation of private entities developing algorithms, products, and services. We must ensure that engineers will create the necessary tools to enable the execution and enjoyment of these rights. For instance, a right to portability means nothing if platforms are not interoperable.[21] Similarly, a right to explanation can only exist if employees of companies relying on algorithms fully understand their functioning, and if they know why an algorithm is being used, what data are used in the algorithm, what data are created by the algorithm, and what variables the algorithm uses to make a decision. Given the limited language of the GDPR on that right, several academics are putting into question even the legal existence and the feasibility of such a right.[22] It seems clear that the GDPR intended to create such an avenue for users but it will be necessary to get further guidance from data protection authorities and stakeholders on how to interpret the text in practice. In short, creating such rights is positive but the conditions for the exercise of those rights must also be developed.

5 DEFINE A CLEAR SCOPE OF APPLICATION

The rights and principles established in a data protection law ensuring users' protection shall apply at all times. This means, for instance, that if an entity is offering a public or private service that involves the processing of data that targets users in the EU, users' rights encompassed under EU law shall apply.

In the digital age, it can be difficult for legislators to ensure sufficient protection of personal data and the rights of users without applying the principle of extraterritoriality. To understand the benefits of the extension of the jurisdictional scope of data protection, we need to look at the issue not from an "establishment" perspective (where is the entity located?) but from a user's perspective (where is the user and where is the user from?). The objective of human rights law, such as data protection frameworks, is first and foremost to protect individuals at all times. It is therefore logical to ensure that users' rights are respected no matter where the entities using people's data are located.

[20] See Chapter 3. European Union, Regulation 2016/679/EU 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) http://eur-lex.europa.eu/legal-content/EN/TXT/?uri=CELEX%3A32016R0679
[21] Article 29 Working Party on Data Protection, Guidelines on data portability. http://ec.europa.eu/information_society/newsroom/image/document/2016-51/wp242_en_40852.pdf
[22] Sandra Wachter, Brent Mittelstadt and Luciano Floridi, University of Oxford, Oxford Internet Institute. Why a Right to Explanation of Automated Decision-Making Does Not Exist in the General Data Protection Regulation. https://papers.ssrn.com/sol3/papers.cfm?abstract_id=2903469

Such application of the territorial scope also has the potential to raise the level of protection for users globally if companies and authorities start implementing data protection and privacy measures in their daily practices worldwide. In terms of competition, such jurisdictional measures can avoid a race to the bottom in terms of protection, whereby certain industries would decide to relocate their companies outside a country to avoid applying user-protective measures.

It is important to note however that extending the jurisdictional scope of a piece of legislation is not without risk and should be carefully considered by lawmakers. Conflicts of laws could arise and certain states could seek to extend the scope of rights-harming measures outside their borders using the same justification. Furthermore, not every entity processing data around the world knows about every country-specific law. It is often unclear whose obligation it is to inform businesses and individuals about their respective obligations and rights. Awareness-raising campaigns shall be conducted to ensure that entities around the world know their obligations. In order for data protection laws to properly function, public authorities need the mandate and resources to carry out public education. Civil society can and should have an active role in the process, in particular to empower people to enforce their rights.

Extending the scope of jurisdiction is not a one-size-fits-all solution and specific criteria should be established in data protection laws to limit bad copies or harmful consequences. Lawmakers should for instance clearly indicate under which scenarios the law applies outside their borders, to which actors specifically, what enforcement mechanisms will be in place, and provide users, companies, and authorities with clear avenues for remedies.

Finally, obligations under data protection law shall clearly apply to both the private and public sector. Public authorities are increasingly collecting individuals' information, getting access to private-sector databases, or otherwise building large databases of personal data. This processing shall be subject to clear obligations for the protection of individuals' personal information, the same way that processing by private entities is regulated.

Experience from the GDPR negotiations

The GDPR extends the territorial scope of the law compared to the 1995 Data Protection Directive. The GDPR applies to any companies and authorities established in the EU but also to entities established outside the EU if those are either processing personal information in connection with the offering of goods or services to, or monitoring of behaviour of, users who are in the European Union.[23] This important change in the scope of application of the law reflects the evolution of EU jurisprudence. For many years, courts in the EU battled with large tech companies that refused to comply with local data protection laws, based on issues of jurisdiction. Google and Facebook have repeatedly argued that they are not covered by data protection laws, for example, in Spain or Belgium, as they were not formally established in these countries. They took this position despite the fact that the companies were mining and monetising personal information from users in these countries.[24] [25] By extending the territorial scope of application, the GDPR sought to respond to these loopholes in protection for users and achieve legal certainty for users. This change is not however without challenges as it is not clear how EU data protection authorities will be able to conduct enforcement actions toward entities located outside the EU and therefore adequately protect rights.

[23] See Article 3. European Union, Regulation 2016/679/EU 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) http://eur-lex.europa.eu/legal-content/EN/TXT/?uri=CELEX%3A32016R0679

[24] Court of Justice of the European Union, Judgement in Case C-131/12, Google Spain SL vs Mario Costeja González, 13 May 2014. http://curia.europa.eu/juris/document/document.jsf;jsessionid=9ea7d0f130d5eb572d024de249578524881c67efe5ec.e34KaxiLc3eQc40Lax-qMbN4PaN0Te0?text=&docid=152065&pageIndex=0&doclang=EN&mode=lst&dir=&occ=-first&part=1&cid=574499

[25] Reuters, Facebook wins privacy case against Belgian data protection authority, June 2016. https://www.reuters.com/article/us-facebook-belgium-idUSKCN0ZF1VV

6 CREATE BINDING AND TRANSPARENT MECHANISMS FOR SECURE DATA TRANSFER TO THIRD COUNTRIES

Data protection frameworks are designed to ensure the free flow of data by establishing adequate mechanisms for data transfer and effective safeguards for users' rights. These mechanisms must be put under strict and transparent oversight and include effective remedies to ensure that the rights of users travel with the data.

Experience from the GDPR negotiations

Under the GDPR, cross-border data transfer outside the European Economic Area may only take place if the transfer is made to a country that has been accorded an adequacy status or when a lawful data transfer mechanism is in place.[26] The GDPR provides for more mechanisms for transfer than the Directive from 1995 through codes of conduct and certification schemes. This approach provides companies with greater flexibility. Effective oversight and enforcement of these mechanisms will be crucial to ensure that users' rights remain protected during and after transfer.

Regarding adequacy, the European Commission has the power to determine whether a third country ensures an adequate level of protection by reason of its domestic law or due to the international commitments into which it has entered, thereby permitting data to be exported to that jurisdiction. Any country can apply for an adequacy decision which will launch a review process conducted at the sole discretion of the EU Commission. Currently, the European Union has granted adequacy to the following countries[27]: Andorra, Argentina, Canada, Switzerland, Faroe Island, Guernsey, State of Israel, Isle of Man, Jersey, New Zealand, United States of America, and Eastern Republic of Uruguay. Adhesion to the Council of Europe Convention 108 is of particular importance in that respect, and is one of the elements taken into consideration in the assessment of the adequacy granting.

In 2016, the US lost the arrangement called Safe Harbour on which its adequacy determination was based due to non-compliance with EU fundamental rights law.[28] The validity of several elements of its new arrangement (EU-US Privacy Shield) continues to be under scrutiny.[29] Other countries like Australia have been requesting an adequacy decision but have so far failed to meet the necessary requirements.[30] Finally, ongoing negotiations for review and new adequacy are currently taking place with Japan.[31]

[26] See Chapter 5. European Union, Regulation 2016/679/EU 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) http://eur-lex.europa.eu/legal-content/EN/TXT/?uri=CELEX%3A32016R0679
[27] EU Commission, Commission decisions on the adequacy of the protection of personal data in third countries http://ec.europa.eu/justice/data-protection/international-transfers/adequacy/index_en.htm
[28] Access Now, CJEU declares Safe Harbor invalid https://www.accessnow.org/cjeu-declares-safe-harbour-invalid/
[29] Access Now, Comments to EU Commission on Privacy Shield review https://www.accessnow.org/cms/assets/uploads/2017/07/AN-PSReviewResponse-1.pdf
[30] European Commission, DG Justice, Comparative study on different approaches to new privacy challenges, in particular in the light of technological developments http://ec.europa.eu/justice/data-protection/document/studies/files/new_privacy_challenges/final_report_country_report_b2_australia.pdf
[31] European Commission, Joint statement by Vice-President Andrus Ansip and Commissioner Věra Jourová on the dialogue on data protection and data flows with Japan, March 2017. http://europa.eu/rapid/press-release_STATEMENT-17-690_en.htm

7 PROTECT DATA SECURITY AND DATA INTEGRITY

To experience the benefits of the digital economy, users need to be able to trust the services they use online. Any data that are shared generates a risk. Therefore, it is increasingly important to ensure that privacy and data protection are considered by engineers in the design phase of product and services and that they are set to the highest standards of protection by default; this is the concept of data protection by design and by default. Those concepts should be spelt out in the law to require entities to adopt them.

Experience from the GDPR negotiations

The GDPR codifies the principles of data protection by design and by default which provides a large number of benefits, such as contributing to data security and integrity.[32] With privacy and data protection by design and by default, companies take a positive approach to protecting users' rights, by embedding privacy-protecting principles into both technology and organisational policy. Privacy and data protection becomes part of the company culture and accountability framework, rather than being a "simple" compliance element. This requires thinking about privacy and data protection from the beginning of the process of developing a product or service.[33] This approach can help companies save on development costs for products or services. Because engineers and development teams will have considered privacy and data protection at the outset of the development phase, there would be fewer adjustments that would have to be made when a legal team reviews the final product. It also reduces the risk of a company being sued for privacy violations or suffering reputational damage due to data leaks, as it would be able to demonstrate its commitment to users' rights. In short, moving from understanding privacy and data protection as a compliance issue to embedding privacy and data security by design and by default can help companies increase trust in their services.

8 DEVELOP DATA BREACH PREVENTION AND NOTIFICATION MECHANISMS

While data protection frameworks should encourage measures fostering data security and data integrity, data breaches can still take place. Measures to address, remedy, and notify users of such problems shall therefore be put in place. Data breaches have gained widespread attention as businesses of all sizes become increasingly reliant on cloud computing and online services. With personal and sensitive data stored on local devices and on cloud servers, breaching network and information security has become attractive to those seeking to expose or exploit private information or demand a ransom. Data breaches have existed for as long as individuals' private records have been maintained and stored. Before the digital era, a data breach could be something as simple as viewing an individual's file without authorisation, or finding documents that weren't properly disposed of.[34] With the digitisation of records and ever-growing personal data collection, the scale of data breaches has skyrocketed, putting users' personal information at greater risk.

[32] See Article 25. European Union, Regulation 2016/679/EU 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) http://eur-lex.europa.eu/legal-content/EN/TXT/?uri=CELEX%3A32016R0679
[33] For more information on Privacy by Design see Ann Cavoukian, Privacy by Design, the 7 Foundational Principles https://www.ipc.on.ca/wp-content/uploads/Resources/7foundationalprinciples.pdf
[34] Nate Lord, The history of data breaches, July 2017. https://digitalguardian.com/blog/history-data-breaches

To prevent and mitigate these risks, mechanisms for data breach notification and prevention of such breaches should therefore be developed, either within a data protection framework or in complementary legislation. High-profile incidents of personal data loss or theft across the globe have prompted wide debate on the level of security given to personal information shared, processed, stored, and transmitted electronically. In that context, gaining and maintaining the trust of users that their data are secure and protected represents a key challenge for organisations. The NGO Privacy Rights Clearinghouse have recorded 7,619 data breaches that have been made public since 2005 in the US alone.[35] This means that at least 926,686,928 private records have been breached in the US since then. IBM and Ponemon Institute report that in 2017 the global average cost of a data breach is $3.62 million.[36] While this cost has slightly decreased compared to last year, the study shows that companies are having larger breaches. Other studies estimate that the average cost of a data breach will be over $150 million by 2020, with the global annual cost forecast to be $2.1 trillion.[37] This means that preventing and mitigating data breaches is not only good for users, but also good for businesses in order to save costs.

Experience from the GDPR negotiations

Data breach notification requirements were introduced in the European Union for the electronic communication sector in 2002.[38] Further specific sectoral rules have been developed since then to serve until those measures are harmonised under the GDPR to facilitate compliance for organisations.

The measures adopted under the GDPR require an organisation to report a data breach "without undue delay" and where feasible within 72 hours after it becomes aware of the incident.[39] While it is clear that the objective of the measure is to ensure that data breaches are reported as quickly as possible, the language is vague. The GDPR then describes the steps that any organisation encountering a breach must follow and provides for the possibility of notifying users. Such notifications are positive from an accountability and transparency perspective and are also crucial to ensure that users can take appropriate action to secure their information and seek remedy if necessary. However, the GDPR leaves it up to organisations to determine whether to notify users of a breach based on their own risk assessment of users' rights and freedoms. Notification to users should be a requirement for any data breach of personal data, which includes not only subscriber information, but other personal data such as photos. Notification should be timely, easy to understand, and comprehensive, and remediation options should be clearly indicated and accessible. By leaving too much discretion to organisations, this provision falls short of empowering users to take control of their information. Organisations suffering a data breach have an obvious economic interest in downplaying the risks associated with a breach and not notifying users, which could result in unaddressed data protection violations. We encourage lawmakers around the world to avoid those shortcomings and develop unambiguous data breach prevention and notification mechanisms.

[35] Privacy Rights Clearinghouse, Data Breaches. https://www.privacyrights.org/data-breaches
[36] Ponemon Institute for IBM, 2017 Cost of Data Breach Study: Global Overview https://www.ibm.com/security/data-breach/
[37] The Experian, Data Breach Industry Forecast, 2015. https://www.experian.com/assets/data-breach/white-papers/2015-industry-forecast-experian.pdf
[38] European Union, Directive 2002/58/EC of the European Parliament and of the Council of 12 July 2002 concerning the processing of personal data and the protection of privacy in the electronic communications sector (Directive on privacy and electronic communications) http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=CELEX:32002L0058:EN:HTML
[39] See Articles 33 and 34. European Union, Regulation 2016/679/EU 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) http://eur-lex.europa.eu/legal-content/EN/TXT/?uri=CELEX%3A32016R0679

9 ESTABLISH INDEPENDENT AUTHORITY AND ROBUST MECHANISMS FOR ENFORCEMENT

No data protection framework can be complete without a robust enforcement mechanism which includes the creation of an independent supervisory authority (data protection authority — DPA — or commission). Even the best data protection law in the world would be close to meaningless without an authority having the powers and resources to monitor implementation, conduct investigations, and sanction entities in case of (repeated, neglected, or willful) data protection violations.

Sanctions should be proportionate to the violations and can be in the form of notice to action. Authorities can for instance request a company stop certain practices that violate users' rights to data protection, such as the failure to provide a privacy policy or selling users' sensitive information without their knowledge and consent.

While punitive fines need to exist, data protection authorities shall apply limited fines to companies, in particular small or medium enterprises (SMEs), that do not engage in significant data processing, do not have the means to understand their obligations to respect data protection law, and have made mistakes out of ignorance rather than malice. Government shall also conduct awareness-raising efforts in order to avoid situations where companies would be ignorant of the existence and relevance of data protection laws. Tunisia, which is currently discussing its first ever data protection law, is proposing a quite innovative gradual approach to sanctions which includes higher fines in cases of recidivism.[40] As a result, a company found to commit data protection violations for which it has already been sanctioned would receive a significantly higher fine.

Sanctions and fines however represent only a small part of the work of DPAs. The role of data protection authorities is of course to enforce data protection laws and conduct oversight but also to assist organisations in their compliance duties. This means that companies, public authorities, and NGOs shall cooperate with data protection authorities to understand each other's duties and obligations. Organisations should not hesitate to establish contact with their DPA which can provide them with resources and materials to help implement the law.

Finally, DPAs have the powers to launch independent investigations into organisations and to hear cases brought to them by individuals or NGOs. In that sense, DPAs act as a guardian for users' rights and can help protect fundamental rights. These authorities are however still largely unknown by users around the world. To further help protect users' rights, NGOs should be empowered to represent users and to independently bring cases in front of DPAs and courts. Governments shall also further promote the work of DPAs, explain their role, and provide them with an adequate budget to ensure that DPAs can fulfil their duties.

Experience from the GDPR negotiations

The European Union and its member states have had data protection laws for almost 30 years. Despite this, many companies were ignoring them due to the lack of enforcement powers for data protection authorities and the relatively low level of fines (up to 150.000€).[41] For years in Europe, legal advisers often advised companies not to comply with EU data protection law, as the risk of being fined was as low as the amount they would have to pay.[42] This blatant disregard for fundamental rights was addressed under the GDPR by raising the fine level to a maximum of 4% of the worldwide turnover of the company.[43] The enforcement powers and the functioning of the DPAs have also been clarified and harmonised. DPAs will now be gathered within a European Data Protection Board which allows them to, for instance, conduct joint investigations across different EU countries.

[40] Tunisia national authority for the protection of personal data. Article 211. Projet de loi relative à la protection des données personnelles, 2017. http://www.inpdp.nat.tn/Projet_PDP_2017.pdf
[41] European Union. Directive 95/46/EC of the European Parliament and of the Council of 24 October 1995 on the protection of individuals with regard to the processing of personal data and on the free movement of such data http://eur-lex.europa.eu/legal-content/EN/TXT/?uri=CELEX:31995L0046
[42] See Panel discussion at Computer, Privacy and Data Protection, Brussels, 2015. https://www.youtube.com/watch?v=sikwHfoiylg
[43] See Chapters 7 and 8. European Union, Regulation 2016/679/EU 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) http://eur-lex.europa.eu/legal-content/EN/TXT/?uri=CELEX%3A32016R0679

10 CONTINUE PROTECTING DATA PROTECTION AND PRIVACY

Having a comprehensive law is a great milestone, but it does not mean governments should stop here in the protection of personal data and privacy. New challenges to privacy and data protection are likely to emerge during implementation phases even if governments aim at making laws "future-proof." This means that a review process will likely be necessary, which is a great opportunity to update the law, address any potential issues with compliance, and provide additional clarity and legal certainty where needed.

It is also important to understand a data protection law as a floor and not a ceiling in the protection of users' rights. This means that organisations must comply with the law, as a minimum, but should also be encouraged to go beyond and take further actions to protect people's privacy. Similarly, depending on the structure and form of the government of a country, different approaches to data protection and privacy can be taken into account. For instance, in the US, the federal government should not prevent local governments and states from providing for user protections, in addition to the limited measures provided at the federal level, and refrain from using its power to preempt regional and local laws.[44] However, in the case of the European Union, member states shall avoid creating additional rules as this would risk fragmenting the harmonised high level of protection for users agreed under the GDPR.

Experience from the GDPR negotiations

Since 1995, EU member states have adopted different local data protection laws based on the benchmark provided by the EU Data Protection Directive. This EU law was completed at a time when only 1% of the population was online, and it was in urgent need of modernisation when the EU Commission proposed the EU General Data Protection Regulation in 2012.[45] It took almost five years of negotiations for lawmakers to agree to the new measures in the law which will become directly applicable from May 2018 (unlike a Directive, which needs to be transposed into national law, a Regulation is directly enforceable). All 28 national data protection laws will be replaced by this single law that provides for harmonised rights and rules across the EU. While this system works under the EU's legal order, it might not be the ideal scenario in other regions or countries. Supranational laws can be difficult to agree upon and might not necessarily be the best instrument to protect users. There is therefore no ideal model for a law but all data protection laws shall take into account all the points laid down in this paper.

[44] EPIC, Privacy preemption watch. https://epic.org/privacy/preemption/
[45] European Commission, Reform of EU data protection rules, 2012. http://ec.europa.eu/justice/data-protection/reform/index_en.htm

DON'TS

Below you will find five recommendations for policy makers to follow when developing a data protection law. We advise caution on the following five elements which, if ignored, could limit the benefits of the proposed law or harm individuals' rights.

1 DO NOT SEEK BROAD DATA PROTECTION AND PRIVACY LIMITATIONS FOR NATIONAL SECURITY

Governments not only have an obligation but also a security interest in ensuring the protection of personal data, in particular when information is held by government agencies. In 2015, as the result of a cybersecurity incident in the US, 21.5 million records of federal employees and family members stored at the Office of Personnel Management were stolen.[46] As these types of incidents and attacks are increasing globally, countries have must take measures to better protect individuals' information.

Despite this, governments often seek limitations to data protection and privacy rights for their own use of personal data by asking for broad exceptions. These exceptions must be prevented and limited to clearly defined, necessary, and proportionate measures that include judicial oversight and accessible remedy mechanisms. Legislation should not give governments and public entities the capacity to shield themselves from the obligation to protect users' right to data protection. Countries have a security interest in safeguarding personal data held by government agencies.

Experience from the GDPR negotiations

The GDPR provides a list of reasons that member states can rely on to restrict users' rights and freedoms protected under the law, such as national security or defence.[47] While it is common to find provisions allowing states to restrict rights in every piece of EU and national legislation, the language of these provisions is often purposefully vague and can potentially cover a wide range of state activities. The GDPR for instance allows for restrictions of rights for broad and undefined "other important objectives of general public interest of the Union or of a Member State". Given the impact of such restrictions on users' rights and freedoms, they should be clearly defined and limited in law, subjected to strict transparency and oversight criteria, and be necessary and proportionate measures in a democratic society.

2 DO NOT AUTHORISE PROCESSING OF PERSONAL DATA BASED ON THE LEGITIMATE INTEREST OF COMPANIES WITHOUT STRICT LIMITATIONS

Companies often argue that they should have a right to collect and process user data, when this is their "legitimate interest", without having to notify users. Unless such exceptions are defined as being exceptions (not the case under the GDPR or the 1995 Directive) and narrowly defined (which is better achieved in the GDPR), this should not be allowed. Otherwise, this intrinsically contradicts the objective of data protection, which is to put users in control of their information. Such attempts to limit users' rights must be prevented.

[46] Patricia Zengerle, Megan Cassella, Millions more Americans hit by government personnel data hack, Reuters, 2015. https://www.reuters.com/article/us-cybersecurity-usa/millions-more-americans-hit-by-government-personnel-data-hack-idUSKCN0PJ2M420150709
[47] See Article 23. European Union, Regulation 2016/679/EU 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)

Experience from the GDPR negotiations

Organisations' legitimate interest is one of the legal bases that can be used to process personal data under the GDPR.[48] The core of data protection is users' control and predictability in the use of their data. The legitimate interest provision goes against these principles. Under "legitimate interest" an organisation is authorised to collect and use personal information without having to notify the concerned users. If you don't know that an entity holds data about you, how could you exercise your right to access the data or your right to object?

This provision was one of the most debated during the negotiations of the GDPR. Companies were defending a broad and vaguely defined provision for legitimate interest and civil society was trying to remove it or significantly limit its scope. Lawmakers tried to limit the impact of the provision in the last months of negotiations by including a requirement for companies to balance their legitimate interest with fundamental rights. While the intention is laudable, companies will conduct this assessment at their own discretion and users could be kept in the dark. The final result is satisfying for no one as businesses wanted even more flexibility than accorded in the text and corresponding recitals, and NGOs wanted clear limitations. We understand the need to provide companies with measures that allow them to conduct business, however, measures that prevent users from having control over their personal information shall be excluded as they contradict the spirit and objective of a data protection law.

3 DO NOT DEVELOP A "RIGHT TO BE FORGOTTEN"

The "right to be forgotten" or "right to de-list" emerges from EU data protection law including the "Google Spain" ruling.[49] This right allows users under certain circumstances to request search engines to de-list web addresses from results when a search is done using their names. This right should not be confused with the right to erasure which allows individuals to delete all personal data related to them when they leave a service or application. The right to erasure is essential to ensure user control over personal information. It also should not be conflated with any take-down measure since the right to be forgotten developed under EU jurisprudence does not require or request any online content to be removed from the web or from search engine indexes.

The way several governments internationally have, accidentally or otherwise, misinterpreted the right to de-list or sought to extend its scope to limit freedom of expression or of information poses a significant threat to human rights. Courts and legislators around the world have demonstrated significant interest in developing measures to establish a "right to be forgotten" which significantly deviates from the approach developed by EU

[48] See Article 6. 1. (f). European Union, Regulation 2016/679/EU 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) http://eur-lex.europa.eu/legal-content/EN/TXT/?uri=CELEX%3A32016R0679

[49] Court of Justice of the European Union, Judgement in Case C-C-131/12, Google Spain SL vs Mario Costeja González, 13 May 2014. http://curia.europa.eu/juris/document/document.jsf;jsessionid=9ea7d0f130d5eb572d024de249578524881c67efe5ec.e34KaxiLc3eQc40Lax-qMbN4PaN0Te0?text=&docid=152065&pageIndex=0&doclang=EN&mode=lst&dir=&occ=-first&part=1&cid=574499

courts, mandating content removal.[50] [51] [52] Any so-called right to be forgotten measure that would lead to deletion of online content is a gross misinterpretation of the right. Under no circumstances must the right to de-list be applied to enable the removal of online content. Similarly, data protection authorities shall not be authorised to request the deletion of online information without the oversight of a judge that can ensure that all fundamental rights, including the right to free expression and freedom to access information, are respected.

Access Now opposes any development of such a "right to be forgotten". If however a right to de-list similar to the one in place in the EU were to be considered by lawmakers, Access Now has identified a series of legal safeguards that lawmakers must put in place to further mitigate the risks of abuse and harms to human rights.[53]

Experience from the GDPR negotiations

The right to be forgotten was added to the right to erasure in the GDPR.[54] The right to be forgotten codifies the jurisprudence of the EU Court of Justice in the "Google Spain" case.[55] The court has developed a set of criteria for search engines to consider when they receive a de-listing request. Search engines must grant a de-listing request only if the personal information included in the designated web address is "inadequate, irrelevant, or no longer relevant, or excessive", and only if the information does not pertain to a public figure or is not of public interest. However, information or links shall not be removed from the search index. They must remain accessible when users conduct searches using terms other than the name of the individual making the de-listing request. Importantly, the GDPR also clarifies that information shall not be de-listed if it is necessary for exercising the right of freedom of expression and information.

Despite those safeguards, further guidance from the EU and its member states is necessary to ensure that search engines do not "over- or under-comply" with the law and the ruling. Uncertainty regarding the geographical scope of application of the right to be forgotten has for instance led to new legal proceedings.[56] For their part, search engines should be more transparent about the criteria they have been using internally to deal with these requests.

Finally, in the current implementation of the right to de-list in the EU, access to remedy is limited. The only form of recourse that a user has is the opportunity to challenge a search engine's decision to deny a request to de-list. There should be more clarity on existing avenues for remedy, and these should be extended.

[50] Access Now, O direito ao esquecimento no Brasil: quais os riscos para os direitos humanos? https://www.accessnow.org/o-direito-ao-esquecimento-no-brasil-quais-os-riscos-para-os-direitos-humanos/
[51] Access Now, Documento de posición: El "derecho al olvido" y su impacto en la protección de los Derechos Humanos https://www.accessnow.org/documento-de-posicion-el-derecho-al-olvido-y-su-impacto-en-la-proteccion-de-los-derechos-humanos/
[52] Access Now, In India, the "right to be forgotten" is in the hands of the Delhi High Court https://www.accessnow.org/india-right-forgotten-hands-delhi-high-court/
[53] Access Now, Understanding the right to be forgotten globally, September 2016 https://www.accessnow.org/cms/assets/uploads/2016/09/Access-Not-paper-the-Right-to-be-forgotten.pdf
[54] See Article 17. European Union, Regulation 2016/679/EU 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) http://eur-lex.europa.eu/legal-content/EN/TXT/?uri=CELEX%3A32016R0679
[55] Access Now, FAQ on the right to be forgotten, 2014. https://www.accessnow.org/cms/assets/uploads/archive/docs/GoogleSpainFAQRtbF.pdf
[56] Access Now, Only a year until the GDPR becomes applicable: Is Europe ready? https://www.accessnow.org/year-gdpr-becomes-applicable-europe-ready/

4 DO NOT AUTHORISE COMPANIES TO GATHER SENSITIVE DATA WITHOUT CONSENT

Given the importance of sensitive data, a higher level of protection than for the rest of personal data must be required to guarantee an adequate level of control for individuals. Therefore, the collection and processing of sensitive personal data shall only be authorised if individuals have given their explicit, informed consent and have the right to withdraw that consent subsequently.

Sensitive data encompasses a wide range of personal information such as ethnic or racial origin, political opinion, religious or other similar beliefs, memberships, physical or mental health details, such as genetic or biometric data, information about personal life and sexuality, or criminal or civil offences. The particular nature and relevance of this information means that users should always be able to control who gets access to and use of this information. As a result, the processing of sensitive information should only be authorised if users have freely given informed and explicit consent. To protect the essence of users' fundamental rights to privacy and data protection, no exception to these rules shall be allowed.

Experience from the GDPR negotiations

The GDPR requires organisations to obtain the explicit consent of the user for the collection of sensitive data as a general basis. While this is extremely positive, the law also authorises the collection and use of sensitive data without users' consent for some specific objectives, including "scientific or historical research purposes or statistical purposes".[57] This broad exception deprives users of control over their most intimate information and is even more problematic in the context of the growth of the e-health industry, large scale, Big Data analysis of political views, and more. If not limited, companies could get a hold of millions of pieces of sensitive information over the next few years, initially to conduct research and gather statistics on their products. In practice, it would be complex to conduct oversight of how organisations use these data, as users will not be informed. Users must be able to control which organisation has access to their health or voting records. This type of loophole must be avoided, or at least strictly limited by restricting the use of these data for research, and statistical research must be conducted in the public interest under strict oversight.

5 DO NOT FAVOR SELF-REGULATION AND CO-REGULATION MECHANISMS

For many years, companies and entities collecting data have been calling for regulation of privacy and data protection not through binding frameworks but rather through self- or co-regulation mechanisms that offer greater flexibility. Despite several attempts, there are no examples of successful non-binding regimes for the protection of personal data or privacy that have been positive for users' rights or, indeed, business as a whole.

As more data are being shared online and off, it is high time to develop mandatory frameworks for data protection and privacy all around the world to prevent or end these behaviours and put users back in control of their information. This will also enable the development of privacy-friendly innovation which is currently limited to a small number of companies that have undertaken a long-term engagement approach to protect their users instead of basing their business model in monetising users' private information.

[57] See Article 9.2.(j). European Union, Regulation 2016/679/EU 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) http://eur-lex.europa.eu/legal-content/EN/TXT/?uri=CELEX%3A32016R0679

Business models built on privacy can serve as a competitive advantage. In countries without overarching data protection laws, companies could innovate through their internal practices by developing voluntary safeguards and guidelines to improve people's trust in the digital economy. Even though self-regulation is inadequate as an enforcement mechanism and unsustainable for safeguarding individuals' rights, it can be beneficial in certain circumstances for both companies and individuals to adopt a voluntary framework in those countries. It cannot be relied upon, either from the perspective of individuals or businesses, due to the risk of "free-riding" by bad actors that will undermine privacy, trust, innovation and take-up of new products.

Experience from the GDPR negotiations

The European Union has a long experience of failed self- or co-regulation attempts in the area of free expression.[58] In the field of privacy and data protection, however, the EU has been a pioneer in the development of a high-level of protection for users. The GDPR is yet another example of that success. While far from perfect, the GDPR is a key instrument for the protection of fundamental rights in the EU, and reflects years of experience gleaned from the implementation of past laws and jurisprudence developed by courts. The GDPR creates clear and strong obligations for organisations but also introduces several accountability tools to further data protection rights such as the principles of data protection by design and by default and new provisions for company certification and industry-wide code of conduct schemes. Such tools aim to develop a vision of data protection beyond mere compliance with the law and encourage innovation in the field.

[58] EDRi, Human rights and privatised enforcement https://edri.org/wp-content/uploads/2014/02/EDRi_HumanRights_and_PrivLaw_web.pdf

CONCLUSION

Access Now wholeheartedly supports the development of local, regional, and international frameworks for the protection of personal data. These frameworks must be user-centric and focus on safeguarding and strengthening rights, while delivering clear and predictable rules for public and private entities to comply with. Last, but not least, we cannot highlight enough the importance of comprehensive and robust enforcement mechanisms overseen by an independent authority to ensure that the proposed protections are fully functional.

Protecting data protection globally has been a long-time area of focus for Access Now, and it continues to be one of our highest priorities. Among other issues, our team is actively engaged in the implementation of the GDPR, the reform of the data protection legislation in Argentina, and negotiations in India and Tunisia for developing a first data protection law.

CREATING A DATA PROTECTION FRAMEWORK:
A DO'S AND DON'TS GUIDE FOR LAWMAKERS

This paper is an Access Now publication.

For more information, please visit: **https://www.accessnow.org,** or
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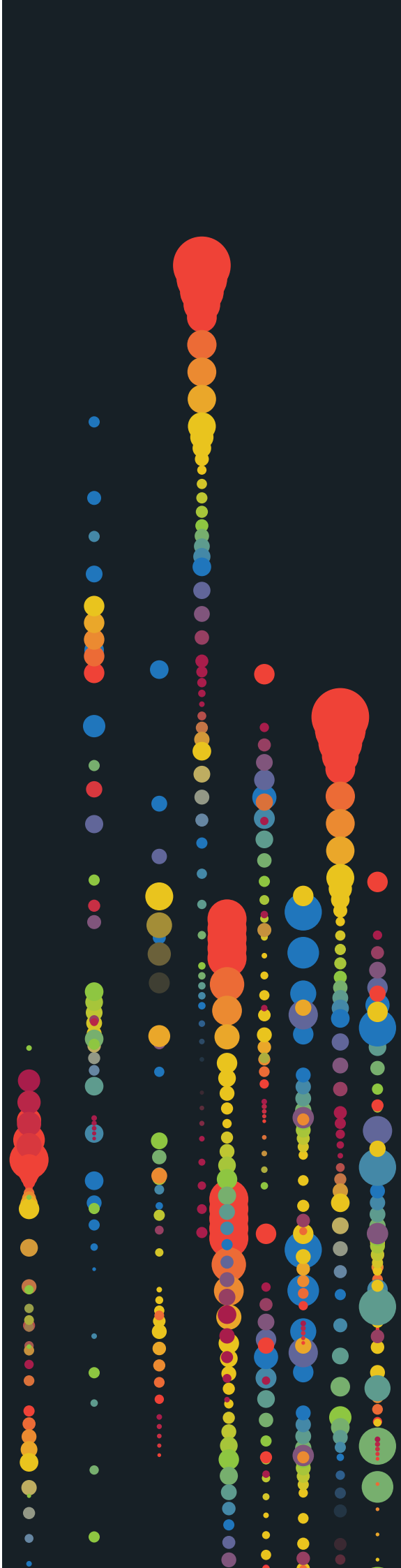

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Access Now defends and extends the digital rights of users at risk around the world. By combining direct technical support, comprehensive policy engagement, global advocacy, grassroots grantmaking, and convenings such as RightsCon, we fight for human rights in the digital age.

https://www.accessnow.org

Appendix C

A USER GUIDE TO DATA PROTECTION IN THE EUROPEAN UNION

Your rights & how to exercise them

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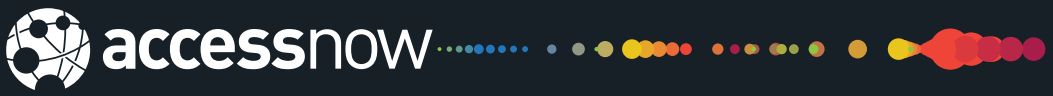

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WHAT YOU WILL LEARN IN THIS GUIDE

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Introduction

GDPR, the new data protection law

What is the General Data Protection Regulation?

Protecting **your personal data rights** in the European Union

What are my rights?

THE RIGHT TO

- information
- access
- rectification
- restrict processing
- erasure
- object
- an explanation
- data portability

How can I exercise my rights?

What to do if my rights are violated and my data misused?

- file a **complaint**
- file a **case in court**
- get **NGO representation**

Conclusion

Take control, exercise your rights!

INTRODUCTION

Access Now presents **A user guide to data protection in the European Union - Your rights and how to exercise them** to help you exercise your right to data protection. This guide gives you information about the rights encompassed under the EU law on data protection as well as information on how to use these rights.

The European Union General Data Protection Regulation is a positive framework for users' protection and can help you take back the control of your personal information. This law replaces and strengthens the 1995 Data Protection Directive. Access Now is a strong supporter of the GDPR. In fact, we worked with lawmakers in Europe to strengthen users' protections throughout the introduction, negotiations, and adoption of the law. After almost five years of debate, the GDPR became applicable on 25 May 2018. With this guide, we aim to contribute to the long-term mission of the GDPR by giving you the necessary information and tools to exercise your rights.

We invite you to read this guide carefully, so you can use your rights to make data protection a reality.

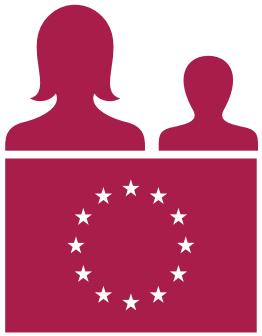
Brussels, July 2018

WHAT IS THE GENERAL DATA PROTECTION REGULATION?

Personal data is any information relating to you, whether it relates to your private, professional, or public life. In the online environment, where vast amounts of personal data are shared and transferred around the globe instantaneously, it is increasingly difficult for people to maintain control of their personal information. This is where data protection and laws such as the GDPR come in.

Data protection refers to the practices, safeguards, and binding rules put in place to protect your personal information and ensure that you remain in control of it. In short, you should be able to decide whether or not you want to share some information, who has access to it, for how long, and for what reason, and to be able to modify some of this information, and more. In the EU, these rules are defined under the General Data Protection Regulation. The GDPR is a user-centric law which aims to put you back in control of your personal data, providing for the **broad spectrum of users' rights** presented in this guide.

WHAT IS THE GENERAL DATA PROTECTION REGULATION?



Under the GDPR, both private companies such as Facebook, Microsoft, Dropbox, Amazon, or Spotify and government bodies have the obligation to ensure the protection of your personal data. **To be protected under the GDPR, you have to either be a citizen of the European Union or be located in the EU, no matter where you are from.**

The GDPR comes with a **robust enforcement mechanism** which empowers **data protection authorities** to investigate data practices and fine companies or public entities up to 4% of their total worldwide annual turnover if they ignore their legal obligations and commit repeated, serious infringements of your rights. These fines are significant and proportionate to the gravity of the infringement on individuals' fundamental rights. For far too long, a handful of companies have been diligently ignoring the EU's data protection norms, which have been in place since 1995. With this new framework, the data protection authorities are better equipped to deal with free riders.

THE RIGHT TO INFORMATION

When a company, a government body, or an organisation collects and uses information about you, you have the right to get information about:

- the **name of the entity** using your data,
- the **contact information** of the person or department in charge of personal data protection at this entity,
- the **reason** for which the entity will use your data,
- the **type of personal data** the entity holds about you,
- the **length of time** your data will be kept,
- **whether your data will be shared** with third parties and who they are,
- **whether your data will be used for automated decision-making** via algorithms,
- **whether data will be moved** outside the EU,
- your **other basic data protection rights**,
- your **right to file a complaint**, and
- **what legal basis has been used to authorise the collection and use of your personal data.** There are six legal grounds authorising entities to use personal data under the GDPR, such as your explicit and informed consent or the execution of a contract.

All this information should be provided to you in a concise, transparent, intelligible way, using clear and plain language. This means that an entity must have terms of service and a privacy policy that are easily understood, which has not typically been the case.

Relevant article under the GDPR: Articles 12, 13, and 14.

THE RIGHT OF ACCESS

No matter how your information was collected, you have the right to ask for and obtain information from a company, a government body, or an organisation as to whether it holds any personal data about you.

If an entity has information about you, you then have the right to be provided, free of charge, a copy of your data and any relevant additional information regarding the reason your information was collected and used, how long it has been kept, whether it was disclosed to a third party, and more. Unless you ask otherwise, you will be provided a copy of your data electronically (e.g., via email or online forms).

You can exercise this right several times at reasonable intervals, but if your requests are repetitive, an entity may ask a fee from the second request. Keep in mind that this right is not absolute. If your request impacts the rights and freedoms of others, you may receive only a partial copy of this information, or none. However, the entity shall explain why it was not possible to provide you with the information.

Relevant article under the GDPR: Article 15

THE RIGHT TO RECTIFICATION

You have the right to amend and modify the information that a company, government body, or organisation has about you if this information is incorrect, incomplete, or inaccurate (for instance, if you have changed your contact details or residence).

Once you have notified the entity, it has the obligation to change your information within a month. During this period, the entity can refuse to modify the information but must then notify you and explain why.

Relevant article under the GDPR: Article 16

THE RIGHT TO RESTRICT PROCESSING

Under certain circumstances, you have the right to request that a company, government body, or organisation stop using or limit the use of information about you so that you can verify the way that the entity is using it.

As an example, you can exercise this right when:

- it is unclear whether and when personal data about you will be deleted,
- the accuracy of the data is contested,
- the data is no longer needed for the purposes it was originally collected but it cannot be deleted because of legal obligations, and
- you have exercised your right to object to the use of your data altogether but the decision is pending.

In addition, when you have consented to use of your personal data, you have the right to withdraw that consent at any time by notifying the entity.

Relevant article under the GDPR: Article 18

THE RIGHT TO ERASURE

You have the right to ask for the deletion of your personal data when:

- a company, government body, or organisation holds information about you that is no longer needed (for instance, if you have chosen to leave a service or a platform), or
- your data has been used unlawfully.

In addition, personal data that you provided before you were 16 years old can be deleted at any time at your request. The age requirement for children may vary in some EU states from 13 to 16 years old.

Keep in mind that when you ask that your data be deleted, companies may retain information they have created based on your data. For instance, a company like Facebook that creates profiles or makes assumptions about you based on your "likes" or browsing habits may keep that information. We encourage you to request deletion of this information explicitly when you leave a platform, and if they fail to act, to bring a complaint.

Relevant article under the GDPR: Article 17

THE RIGHT TO OBJECT

You have the right to object to the collection, use, and storage of your personal data by a company, government body, or organisation when:

- **your data is being used for direct marketing** (After your request, the entity must stop using your personal data and comply with your request free of charge.),
- **your data is being used for automated decision making**, including profiling, where no human intervention or review will take place,
- **your data is being used for scientific or historical research and statistics**, and
- **your data is being used for an entity's "legitimate interest" or in carrying out a task in the public interest**.

In the last two scenarios, your right to object may be limited if the entity can demonstrate that the use of your data is necessary and that the reason for using it overrides your interests, rights, and freedoms.

Your right to object to use of your data for decision-making that is based solely on automated processes is perhaps one of the most important rights in the era of big data. Through techniques like profiling, your information is gathered to be evaluated, analysed, and used to predict your behaviour and make assumptions about you. This practice is fundamentally contrary to your right to privacy and can be highly discriminatory.

Even if your right to object is limited under national laws, we encourage you to exercise this right and bring a complaint if necessary.

Relevant article under the GDPR: Article 21

THE RIGHT TO AN EXPLANATION

When your data is used to make a decision about you, with an automated process such as the use of algorithms, you have the right to be given an explanation about its functioning. While the GDPR does not spell out details about the information you should receive, we recommend that you at least request:

- the information that was entered into the automated system,
- the reason for the use of the automated system (for example to calculate a credit or insurance rate, or decide on hiring),
- the objective of the use of the automated system (for example to speed up processes, or to limit mathematical errors),
- whether a human intervention and review of the process and decision will take place (if not, you have the right to object to the use of such an automated system), and
- your ability to challenge the decision made through use of the automated system, and to ask for a review.

Relevant article under the GDPR: Recital 71, Articles 13 to 15

THE RIGHT TO DATA PORTABILITY

You have the right to move your data from one service to another, and as such, to receive a file with your information in a structured, commonly used, and machine-readable format. This means that if you wish to move to a new social media platform, for example, you can do so quickly and easily by taking your data from the old platform to the new one. When it is technically feasible, you can directly request that your personal data be transferred to another company whose services you would like to use. This right relates only to information that you have provided to companies. Any data that companies collect or create based on your data will not necessarily be provided in a portable file.

This right is a novelty under data protection law and can help foster innovation and competition in the digital era, since it allows users to more easily switch between platforms. However, in order for this right to deliver its promise and for users and innovators to truly benefit from it, it will be important to develop and implement interoperability standards between services. This means that platforms should use a similar format for entering data.

Relevant article under the GDPR: Article 20

HOW CAN I EXERCISE MY RIGHTS?

You can exercise all the rights mentioned above by sending an email to any company, government body, or organisation that holds data about you.

Most entities have a dedicated email address that you can use to exercise your rights which can be found in the terms of service or privacy policies that are required to be available online. We know these policies are typically long (although this should improve under the GDPR). However, we encourage you to take a look and search for a contact address. If you cannot find contact information, that conflicts with your right to information and you can bring this matter to a data protection authority (see next point).

The email could be as simple as follows:

Dear xxx,

Pursuant to the EU General Data Protection Regulation, I would like to exercise my right to withdraw consent to the processing of my data / right of access / right to erasure / right to object to the processing of my data / right to rectification / right to restrict processing / right to an explanation / right to portability, linked to my name and/or email address.

I look forward to hearing back from you.

Best regards,
xxx

HOW CAN I EXERCISE MY RIGHTS?

Below are some examples of points of contact provided by companies for you to exercise your rights. We are giving examples from different industries, not just the technology industry, since the GDPR applies to any entity collecting data about you.

For Thalys, contact the company data protection officer at data.protection@thalys.com

For Eurosport, contact the platform data protection officer at DPO@discovery.com

For Zalando, you can find a specific contact information based on your spoken language in Chapter 13 of the company's privacy statement: https://www.zalando.be/zalando-privacy-statement/#chapter-13

For British Airways, you can request a copy of your data at DPO@ba.com. You can also verify and modify the way that British Airways uses your data at: https://www.britishairways.com/travel/permissionscentre/public/

For Palantir, send an email to data-subject-request@palantir.com

For the Belgian Passenger Information Unit, which collects, uses, and retains data for five years when a traveler enters the country by plane, boat, train, or bus, you can contact the data protection office at belpiu.dpo@ibz.fgov.be or DPO - Leuvenseweg 1, 1000 Brussels.

Google allows you to exercise some of your rights through its privacy policies: https://policies.google.com/privacy?hl=en&gl=be#infochoices and you can also send an email to Google's data protection office via this form: https://support.google.com/policies/contact/general_privacy_form. We also encourage you to take a few minutes to review and adjust controls for how and when Google can use your information, both for your account https://myaccount.google.com/privacycheckup and specifically for the use of ads https://adssettings.google.com/authenticated?hl=en

WHAT CAN I DO IF MY RIGHTS HAVE BEEN VIOLATED OR MY DATA MISUSED?

You can exercise all the rights mentioned above at any point in time. If you think your data protection rights or other related privacy rights have been breached, you can take legal action, which has been made easier under the GDPR:

You can file a complaint with the data protection authority (DPA) of the EU country where you are located. DPAs are independent public authorities that monitor, supervise, and enforce the application of the GDPR. They are here for you. The DPA has the obligation to inform you about the progress of any complaint three months after you file it. If at any point you are dissatisfied with the response from the DPA handling your complaint, you can bring the authority to court. The table below gives you information and contact points for every DPA in the EU.

You can file a case in court against a company, a government body, or an organisation. You can do this instead of, or in addition to, filing a complaint with your data protection authority.

You have the right for a non-governmental organisation (NGO) to file a complaint on your behalf if the NGO is legally established, its activities are protecting individuals or the public interest, and the NGO has expertise in the area of data protection. This avenue is important to empower you if your complaint or case is lengthy and complex. Having the option of NGO representation opens more avenues for remedy, increasing the chances that violation of your rights will not go unpunished.

WHERE SHOULD I GO IF MY RIGHTS HAVE BEEN VIOLATED OR MY DATA MISUSED?

Austria
Österreichische Datenschutzbehörde
Hohenstaufengasse 3
1010 Wien

Tel. +43 1 531 15 202525
dsb@dsb.gv.at
https://www.dsb.gv.at/

Belgium
Commission de la protection de la vie privée
Rue de la Presse 35
1000 Bruxelles

Tel. +32 2 274 48 00
commission@privacycommission.be
https://www.privacycommission.be/

Bulgaria
Commission for Personal Data Protection
2, Prof. Tsvetan Lazarov blvd.
Sofia 1592

Tel. +359 2 915 3523
kzld@cpdp.bg
https://www.cpdp.bg/

Croatia
Croatian Personal Data Protection Agency
Martićeva 14
10000 Zagreb

Tel. +385 1 4609 000
azop@azop.hr
http://www.azop.hr/

Cyprus
Commissioner for Personal Data Protection
1 Lasonos Street
1082 Nicosia
P.O. Box 23378, CY-1682 Nicosia

Tel. +357 22 818 456
commissioner@dataprotection.gov.cy
http://www.dataprotection.gov.cy/

Czech Republic
The Office for Personal Data Protection
Pplk. Sochora 27
170 00 Prague 7

Tel. +420 234 665 111
posta@uoou.cz
https://www.uoou.cz/

Denmark
Datatilsynet
Borgergade 28, 5
1300 Copenhagen K

Tel. +45 33 1932 00
dt@datatilsynet.dk
https://www.datatilsynet.dk/

Estonia
Estonian Data Protection Inspectorate
Väike-Ameerika 19
10129 Tallinn

Tel. +372 6274 135
info@aki.ee
http://www.aki.ee/en

WHERE SHOULD I GO IF MY RIGHTS HAVE BEEN VIOLATED OR MY DATA MISUSED?

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Finland
Office of the Data Protection Ombudsman
P.O. Box 315
FIN-00181 Helsinki

Tel. +358 10 3666 700
tietosuoja@om.fi
https://tietosuoja.fi/en/home

France
Commission Nationale de l'Informatique et des Libertés - CNIL
8 rue Vivienne, CS 30223
F-75002 Paris, Cedex 02

Tel. +33 1 53 73 22 22
https://www.cnil.fr/fr/plaintes
https://www.cnil.fr/

Germany (Federal)
Die Bundesbeauftragte für den Datenschutz und die Informationsfreiheit
Husarenstraße 30
53117 Bonn

Tel. +49 228 997799 0
poststelle@bfdi.bund.de
https://www.bfdi.bund.de/

Greece
Hellenic Data Protection Authority
Kifisias Av. 1-3, PC 11523
Ampelokipi Athens

Tel. +30 210 6475 600
contact@dpa.gr
http://www.dpa.gr/

Hungary
Data Protection Commissioner of Hungary
Szilágyi Erzsébet fasor 22/C
H-1125 Budapest

Tel. +36 1 3911 400
peterfalvi.attila@naih.hu
http://www.naih.hu/

Ireland
Data Protection Commissioner
Canal House - Station Road
Portarlington
Co. Laois

Tel. +353 57 868 4800
info@dataprotection.ie
https://www.dataprotection.ie/

Italy
Garante per la protezione dei dati personali
Piazza di Monte Citorio, 121
00186 Roma

Tel. +39 06 69677 1
garante@garanteprivacy.it
https://www.garanteprivacy.it/

Latvia
Data State Inspectorate
Director: Ms Signe Plumina
Blaumana str. 11/13-15
1011 Riga

Tel. +371 6722 3131
info@dvi.gov.lv
http://www.dvi.gov.lv/

WHERE SHOULD I GO IF MY RIGHTS HAVE BEEN VIOLATED OR MY DATA MISUSED?

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Lithuania
State Data Protection
Žygimantų str. 11-6a
011042 Vilnius

Tel. +370 5 279 14 45
ada@ada.lt
https://www.ada.lt/

Luxembourg
Commission Nationale pour la Protection des Données
1, avenue du Rock'n'Roll
L-4361 Esch-sur-Alzette

Tel. +352 2610 60 1
info@cnpd.lu
https://cnpd.public.lu/

Malta
Office of the Data Protection Commissioner
2, Airways House
High Street, Sliema SLM 1549

Tel. +356 2328 7100
commissioner.dataprotection@gov.mt
http://www.dataprotection.gov.mt/

The Netherlands
Autoriteit Persoons Gegevens
Prins Clauslaan 60
P.O. Box 93374
2509 AJ Den Haag/The Hague

Tel. +31 70 888 8500
info@autoriteitpersoonsgegevens.nl
https://autoriteitpersoonsgegevens.nl/nl

Poland
The Bureau of the Inspector General for the Protection of Personal Data - GIODO
ul. Stawki 2
00-193 Warsaw

Tel. +48 22 53 10 440
kancelaria@giodo.gov.pl
https://giodo.gov.pl/

Portugal
Comissão Nacional de Protecção de Dados - CNPD
R. de São. Bento, 148-3°
1200-821 Lisboa

Tel. +351 21 392 84 00
geral@cnpd.pt
https://www.cnpd.pt/

Romania
The National Supervisory Authority for Personal Data Processing
B-dul Magheru 28-30
Sector 1, BUCUREŞTI

Tel. +40 21 252 5599
anspdcp@dataprotection.ro
http://www.dataprotection.ro/

Slovakia
Office for Personal Data Protection of the Slovak Republic
Hraničná 12
820 07 Bratislava 27

Tel. + 421 2 32 31 32 14
statny.dozor@pdp.gov.sk
https://dataprotection.gov.sk/uoou/

WHERE SHOULD I GO IF MY RIGHTS HAVE BEEN VIOLATED OR MY DATA MISUSED?

Slovenia

Information Commissioner
Zaloška 59
1000 Ljubljana

Tel. +386 1 230 9730
gp.ip@ip-rs.si
https://www.ip-rs.si/

Spain

Agencia de Protección de Datos
C/Jorge Juan, 6
28001 Madrid

Tel. +34 91399 6200
internacional@agpd.es
https://www.agpd.es/

Sweden

Datainspektionen
Drottninggatan 29
5th Floor
Box 8114
104 20 Stockholm

Tel. +46 8 657 6100
datainspektionen@datainspektionen.se
https://www.datainspektionen.se/

United Kingdom

The Information Commissioner's Office
Water Lane, Wycliffe House
Wilmslow - Cheshire SK9 5AF

Tel. +44 1625 545 745
international.team@ico.org.uk
https://ico.org.uk

CONCLUSION

In the digital era, ensuring that your data are protected is essential. Misuse of data can result in discriminatory decisions, violation of privacy rights, identity theft, fraud, and more. This is why you must be in control of your information. The data protection rights safeguarded under the GDPR and presented in this guide will help put you back in control.

For far too long, data protection laws have been ignored because of weak enforcement mechanisms. Now that the law has changed in the EU, we have a responsibility to help make data protection a reality and hold the entities collecting, using, and storing our data accountable for infringement of our rights. We invite you to use this guide to start exercising your rights.

Additional resources
Want to know more about data protection and the GDPR? Here are some useful resources:

- European awareness campaign: the GDPR explained
  https://gdprexplained.eu
- Access Now's blog post on why data protection matters
  https://www.accessnow.org/data-protection-matters-protect
- EDRi's paper on data protection
  https://edri.org/wp-content/uploads/2013/10/paper06_web_20130128.pdf
- European Commission's tool on the GDPR - citizens' guide
  https://ec.europa.eu/info/law/law-topic/data-protection/reform/rights-citizens_en

accessnow

Access Now defends and extends the digital rights of users at risk around the world. By combining direct technical support, comprehensive policy engagement, global advocacy, grassroots grantmaking, and convenings such as RightsCon, we fight for human rights in the digital age.

https://www.accessnow.org