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PERSONAL DATA AND RESTRICTIONS ON MEDICAL RESEARCH INFORMATION

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ABSTRACT

The research question discussed in this thesis is under what conditions medical research information can be restricted by the Union General Data Protection Regulation (GDPR) and fall under the definition of personal data as defined in the GDPR article 4(1) and the Article 29 Working Party's opinions. This restriction may end up having a slowing effect on the progression of the research and the future of medical science. The definition of personal data provided by the GDPR gives a broad scope to what personal data is. The article 29 Working Party on personal data, gives an opinion on this definition based on the former EU Data Protection Directive, which follows closely to the in-effect GDPR definition. The aim being if medical research information, that inherently is not personal data, may unwillingly be regulated by the data protection regulation because of the broad definition of Personal Data as defined in the GDPR and with the opinions of the Article 29 Working Party's opinion on personal data. This effect is partly due to technological advancements and modernisation of research techniques and data gathering. The amount of information that can be gathered through a single sample only grows with time. The methods being analysing different research articles done by legal scholars and professionals. The findings point towards the conclusion that data acquired through research in the scientific field of health and medicine will possibly have a deeper connection with data protection regulations in the future.

Keywords: Medical research, GDPR, WP 29, personal data

INTRODUCTION

The world we live in today is a world of information. The flow of information is not slowed down even by disease, instead the gathering of data is increased. This can be seen in the ongoing COVID-19 pandemic and the massive amounts of health data that has been gathered about it. Many countries have developed new ways of gathering data such as applications for the coronavirus that share information of health and location to the data processors.[1] The situation has been difficult for many citizens with the increased surveillance and lockdowns of the society, which in turn has had an effect on their health.[2]

The General Data Protection Regulation (GDPR) that came into force on 25 May 2018 has been a model of European data protection to the world by introducing rights for the citizens and obligations to the data processors. The GDPR describes the Union data protection rights and obligations and recognises that everyone has the right to the protection of personal data.[3] Through data there is the possibility to conclude research, which is why this thesis is very topical with the ongoing health concerns around the world and the GDPRs grip on all processing of personal data in the EU. The definition of Personal Data, which will be the centre of the thesis, as "any information relating to an identified or identifiable natural person". The wordings of 'any information' must be considered, which can contain a variety of different data that widens the definition. The words 'relating to', meant to describe how the data should depict its connection to the person, an 'identified or identifiable' meaning that there must be some way of knowing who the person is. It is relevant to notice how the definition really opens the possibility for information not meant to fall under the GDPR to still become personal data within its definition. The Article 29 Working Party on personal data (hereinafter 'the opinion') goes further into the definition of personal data from the old data protection directive (DPD) which follows a very similar definition of personal data as the GDPR today.

The aim of the research is to find out if medical research information, that inherently is not personal data, can still be governed by the GDPR because of the broad definition of Personal Data as defined in the GDPR and with the opinions of the Article 29 Working Party's opinion on personal data. This could happen if the personal data even though it being pseudonymised or

[1] Tzanou, M. (2020). Health Data Privacy under the GDPR. London, Routledge 1st edition. Taylor & Francis group, 2.
[2] Pieh, C., Budimir, S., Probst, T. (2020). The effect of age, gender, income, work, and physical activity on mental health during coronavirus disease (COVID-19) lockdown in Austria. Journal of Psychosomatic Research, vol 136, 1.
[3] Clarke, N., Vale, G., Reeves, E.P., Kirwan, M., Smith, D., Farrell, M., Hurl, G., McElvaney, N.G. (2019). GDPR: an impediment to research? Irish journal of Medical Science, 188, 1129.

anonymised, through technology or more information being provided would allow the research data to relate to an identifiable individual. If data, that by itself does not relate to an individual, is used with the means to be applied towards one individual, it creates the possibility that it becomes personal data as seen by the GDPR. This demonstrates the problem that any data that would be used in medical research in coherence with an individual, would become personal data. The issue is that the definition of personal data in the GDPR would allow unnecessary amounts of data to fall under its authority. This could possibly result in problems in research which leads to the research question. The research question which is under what conditions medical research information can be restricted by the GDPR and fall under the definition of personal data as defined in the GDPR article 4(1) and the Article 29 Working Party's opinions.

Medical research data that falls under the GDPR as personal data has strict processing restrictions where the individual concerned must give consent.[4] The medical research would slow down and become harder to conclude, if consent must be given for every piece of information that could be connected to an individual as explained above.[5]

Some key changes between the DPD and the GDPR were certain territorial restrictions as it mostly processes data within the Union. The changes the GDPR introduced where that all personal data that could be related to an EU citizen is regulated by it. This is the same with the material scope of the DPD which did not regulate processing of information outside of Union law which in turn the GDPR allows.[6] Though the GDPR similarly to the DPD still leaves a lot for *in casu* interpretation which in turn means that every case may bring additional need for interpretation of data protection regulation.[7]

To begin this thesis, I will define and discuss what Personal data and pseudonymisation is. They play a major role in the clarification of the study. The ECJ have provided some interpretations to the topic of personal data which allow the broader interpretation of the definition. While defining pseudonymisation I will also keep the possibility of data anonymisation in mind, even though

[4] Regulation (EU) 2016/679 of the European Parliament and of the Council of 27 April 2016 on the protection of natural persons with regard to the processing of personal data and on the free movement of such data, and repealing Directive 95/46/EC (General Data Protection regulation), published in Official Journal of the European Union, L 119, 4 May 2016, Recital 33.
[5] Rumbold, J.M.M., Pierscionek, B. (2017). The effect of the General Data Protection regulation on Medical Research. J Med Internet Res 2017, 19(2), 2.
[6] Punnagaim, M., Dayalu, P. (2019). GDPR a privacy regime. International Journal of Trend in Scientific Research and development, 3, 714.
[7] Lindqvist, J. (2018) New challenges to personal data processing agreements: is the GDPR fit to deal with contract, accountability and liability in a world of the Internet of Things? International Journal of Law and Information Technology, 26, 62.

processing of anonymized data is not regulated in the GDPR as mentioned in recital 29 of the same regulation. Anonymized is still data which in turn I will argue that could potentially be transformed into personal data again.

The opinion of the Article 29 Working Party on personal data is important for this subject because of the in depth wording that the definition is made out of. I will take apart the definition and explain each part separately to understand the width of the definition. By doing a comparing legal analysis of the similarities of what personal data is according to the DPD and GDPR, and to justify why the Working Party's opinions can be used regarding the GDPR I create the needed information required to further the thesis towards the real question on how it can be applied to medical research.

I will evaluate whether if the definition of personal data is too wide at the moment, by analysing different up to date articles and legal research that have relevant thoughts and information. By qualitative research in articles and journals I will do a critical legal analysis[8] depicting when medical research information can have the properties of personal data and how that information could be restricted by the GDPR. From the analysis I will determine implications and limitations that the wide definition of Personal data can have if it restricts medical research information not meant to be governed by the GDPR. Finally, I will end with a conclusion that summarises the whole paper on if the data protection rules and practices will influence medical research in any negative way.

The thesis consists of the introduction, followed by three main chapters. First the discussion part on what personal data is, and pseudonymised data and anonymised data. The second chapter going into the Article 29 Working Party opinions with four subchapters explaining and splitting the definition of personal data. The last chapter goes into the research question about medical research information and personal data, with two subchapters discussing what kind of data medical research uses and restrictions that can be put on them by the broad interpretation of personal data. Lastly a conclusion to summarise the thesis and give some ideas for the future of this research topic.

[8] Micallef, C. (2018). Critical analysis: a vital element in healthcare research. International Journal of Behavioural and Healthcare Research, 5, 105.

1. DISCUSSION

1.1. What is Personal data

The central idea of this thesis revolves around the term personal data. It is not a term about information in personal possession but reflects the information about a person. This term can also be called personal information or personally identifiable information and is one of the most important notions in modern privacy and data protection law.[9] The GDPR is the data protection regulation introduced in 2016 and came into force in 2018 by the European Union. It is meant to give the consumers more rights and control when it comes to personal data. The regulation is applied to all the processing of personal data of data subjects and to the undertakings functioning as controllers or processors in the Union.

The General Data Protection Regulation (GDPR) defines personal data as following. "*any information relating to an identified or identifiable natural person ('data subject'); an identifiable natural person is one who can be identified, directly or indirectly, in particular by reference to an identifier such as a name, an identification number, location data, an online identifier or to one or more factors specific to the physical, physiological, genetic, mental, economic, cultural or social identity of that natural person."*[10] The definition is mean to be broad to include all necessary manners of information that can relate to a person. All information, in whatever form it is in can potentially become what the definition calls personal data.[11] This could potentially lead to the GDPR becoming a universal regulation on processing of information.[12]

The European Court of Justice has given several interpretations on personal data throughout different cases. These interpretations give a somewhat clearer picture to what constitutes personal data and how broad the definition is. The basics that should be understood is that a person's name, surname, and age are forms of personal data that clearly shows information of an individual. The ECJ has also interpreted in different cases where for example a person's income

[9] Voss, W.G., Houser, K.A. (2019). Personal Data and the GDPR: Providing a Competitive Advantage for U.S. Companies. American Business law Journal ,56(2), 292.
[10] Regulation (EU) 2016/679 of the European Parliament and of the Council of 27 April 2016 on the protection of natural persons with regard to the processing of personal data and on the free movement of such data, and repealing Directive 95/46/EC (General Data Protection regulation), published in Official Journal of the European Union, L 119, 4 May 2016. Art 4(1)
[11] Wong, B. (2019). Delimiting the concept of personal data after the GDPR. Cambridge University Press, Legal Studies, 39, 529.
[12] Ibid, 517.

exceeding a certain threshold as well as any other earnings constitute personal data.[13] A person's hobbies, phone number and working conditions are also valuable information that can be constituted as personal data.[14] To draw a connection to the topic of hand with medical research the ECJ has also made interpretations that personal data is any "name, DOB, nationality, gender, ethnicity, religion and language", even the comments and opinions of an expert in medical research will constitute characteristics of personal information.[15] The possible information constituting personal data is not exhaustive which is why the ECJ provides more conclusive adaptations to personal data depending on case to case.

The step to step interpretation of the definition will be done later in the text, with the opinion of the article 29 Working Party kept in mind.

1.2. Pseudonymised data and anonymised data

The whole world revolves enormously around data, and data are connected to some identifiers. These identifiers are the backbone of personal data. Making it possible to identify a person based on the data provided and the identifiers it carries. Pseudonymisation is the removing of identification attributes from the data so it can no longer be connected to any specific data subject without having the correct additional information to decode it. So, in simple terms, pseudonymisation is the disguising of data and reducing the risk of direct identification. Thus, also the perfect way to use processed personal data in research and scientific studies.[16] The GDPR however gives the definition that pseudonymisation is the act of 'processing' data in a way that does not attribute the data to a specific data-subject any longer.[17] The act of processing is the key word in the GDPR definition of pseudonymisation, where it itself is not data. To simplify the context of it, the wordings of 'pseudonymised data' can be used. This means that it is data that has gone through the process of pseudonymisation.

[13] Judgement of 16 December, Tietosuojavaltuutettu v Satakunnan Markkinapörssi Oy and Satamedia Oy, C-73/70, EU:C:2008:727.
[14] Judgment of 6 November 2003, Criminal proceedings against Bodil Lindqvist, C-101/01, EU:C:2003:596.
[15] Judgement of 16 July 2015, Client Earth ET AL. V. EFSA, C-615/13 P, EU:C:2015:489.
[16] Domingo-Ferrer, J. (2019). Flexible query answering systems, Personal Big Data, GDPR and Anonymization: Springer, Lecture Notes in Computer Science, 11529, 8.
[17] Mourby, M., Mackey, E., Elliot, M., Gowans, H., Wallace, S.E., Bell, J., Smith, H., Aidinlis, S., Kaye, J. (2018) Are 'pseudonymised' data always personal data? Implications of the GDPR for administrative data research in the UK. Computer law & security review ,34, 223.

The definition of the GDPR on personal data, which is "*any information relating to an identified or identifiable natural person…"*[18]*, can be used as an example to better* understand the link of pseudonymisation. The pseudonymised data still relates to an identifiable person but the identifications are removed so that the data cannot be related to a 'specific' natural person without the correct data points.[19] There are many ways to pseudonymise data, but the core idea is to reduce the risk of direct identification. Thus, if using means of encryption for the pseudonymisation it should be random and unpredictable. Even though the idea of pseudonymisation is to remove identifications its main advantage is that the data is still retractable to the identifiable person when having the correct keys for it.[20]

Pseudonymisation is still very useful when it comes to research and statistics because of the fact that you can handle the data 'semi-anonymously', but still be able to trace it back to the data subject if necessary. Pseudonymisation of data works as a safeguard when handling sensitive personal information in research.[21] This is also the reason why the GDPR regulates pseudonymised data, because it is data that can still be identifiable, unlike anonymised data.

Anonymised data is the processing of data that has the result of the data not having the identifiers to be able to identify someone. Differentiating from pseudonymized data the anonymized data should be irreversibly de identifiable to be considered anonymized.[22] The GDPR does not regulate anonymised data because the relationship between data and an identifiable person is not there, as claimed in recital 26 of the GDPR.[23] In essence, anonymized data is the opposite of personal data.[24]

[18] Regulation (EU) 2016/679 of the European Parliament and of the Council of 27 April 2016 on the protection of natural persons with regard to the processing of personal data and on the free movement of such data, and repealing Directive 95/46/EC (General Data Protection regulation), published in Official Journal of the European Union, L 119, 4 May 2016. Art 4(1)
[19] Mourby, M., Mackey, E., Elliot, M., Gowans, H., Wallace, S.E., Bell, J., Smith, H., Aidinlis, S., Kaye, J. (2018) Are 'pseudonymised' data always personal data? Implications of the GDPR for administrative data research in the UK. Computer law & security review, 34, 223.
[20] Article 29 Working Party opinion 4/2007 on the concept of personal data, 20 June 2007, 18.
[21] Mourby, M., Mackey, E., Elliot, M., Gowans, H., Wallace, S.E., Bell, J., Smith, H., Aidinlis, S., Kaye, J. (2018) Are 'pseudonymised' data always personal data? Implications of the GDPR for administrative data research in the UK. Computer law & security review, 34, 223.
[22] Ibid, 224.
[23] Regulation (EU) 2016/679 of the European Parliament and of the Council of 27 April 2016 on the protection of natural persons with regard to the processing of personal data and on the free movement of such data, and repealing Directive 95/46/EC (General Data Protection regulation), published in Official Journal of the European Union, L 119, Recital 26
[24] Purtova, N. (2018). The law of everything. Broad concept of personal data and future of EU data protection law. Law, innovation and technology, 10(1), 4.

Anonymized data should be risk free for researchers to use because it does not contain any identifying information.[25]If a researcher in a medical facility would have a set of medical data that was said to be anonymous and stripped of all identifiers, then it is not regulated by the data protection regulation. But if the researcher would be able to somehow reasonably gain access to more information that could reveal an individual from the data it instantly becomes pseudonymised data which is regulated by the GDPR.[26] The wordings of the GDPR recital 26 is that the determination if an individual is identifiable, is by the controller or a person who uses all the means reasonably likely to identify someone. If the identification from the information provided is not reasonably likely the data should be deemed anonymous.[27] Anonymizing data is not as simple as it sounds, simple deletion of name and address from the information is not usually sufficient to become anonymized data.[28] The recital 26 of the GDPR also mentions how the means reasonably likely to be used in identification takes into consideration the available technology at that time. This means that anonymized data can become personal data if the technology advances to such a level where identification is possible.[29]

[25] El Emam, K., Álvarez, C. (2015). A critical appraisal of the Article 29 Working Party Opinion 05/2014 on data anonymization techniques. International Data Privacy Law, 5(1), 74.
[26] Purtova, N. (2018). The law of everything. Broad concept of personal data and future of EU data protection law. Law, innovation and technology, 10(1), 29.
[27] Harbord, K. (2019). Genetic Data Privacy Solutions in the GDPR. Texas A&M Law Review (7(1)), 289.
[28] Rumbold, J.M.M., Pierscionek, B. (2017). The effect of the General Data Protection regulation on Medical Research. J Med Internet Res 2017, 19(2), 2.
[29] El Emam, K., Álvarez, C. (2015). A critical appraisal of the Article 29 Working Party Opinion 05/2014 on data anonymization techniques. International Data Privacy Law, 5(1), 76.

2. ARTICLE 29 WORKING PARTY OPINIONS

The article 29 working party did a deep analysis in 2007 on the concept of personal data, as defined in the Directive 95/46/EC also called "the data protection directive" (DPD). Why this opinion is relevant now when the GDPR is the in effect data protection regulation in the EU is the very close similarity and harmonisation of the DPD into the GDPR. As Mr. Spindler and Mr. Schemechel writes in their paper that the GDPR does not introduce any major changes when it comes to personal data compared to the DPD.[30] It still follows the same approach where the data either is or is not personal, which means that either the DPD or the GDPR is applicable to the information or it is not.[31]

A bit of background information, the objective of the opinion by the article 29 working party was to get a common understanding of the definition of personal data, where states had different understanding on the concept. The opinion also broadly gives the conclusion that in an evolving world the data protection laws would render everything to become personal data.[32]

2.1. The four building blocks of personal data

The definition of personal data in the DPD is, *"Personal data shall mean any information relating to an identified or identifiable natural person ("data subject"); an identifiable person is one who can be identified, directly or indirectly, in particular by reference to an identification number or to one or more factors specific to his physical, physiological, mental, economic, cultural or social identity"*.[33] The idea is that the definition should be as general as possible so that all data that is identifiable to a person is included. The definition was made inherently flexible so that they could be assimilated to every needed context.[34] We can see that the definition matches the above mentioned GPDR definition of personal data very similarly if not having the exact same meaning.

The working party wanted to give an appraisal of the broadness of the definition and how a lot of data can fall under its scope. The most unfavourable result the broad definition of personal data

[30] Spindler, G., Schmechel, P. (2016). Personal Data and Encryption in the European General Data Protection Regulation. Journal of Intellectual Property, Information Technology and Electronic Commerce Law, 7(2), 165.
[31] Ibid.
[32] Article 29 Working Party opinion 4/2007 on the concept of personal data, 20 June 2007
[33] 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, Official Journal L 281, 23/11/1995, 0031-0050. Art 2(a).
[34] Purtova, N. (2018). The law of everything. Broad concept of personal data and future of EU data protection law. Law, innovation and technology, 10(1), 44.

could have, would be that the directive could regulate data outside of its purpose, regulate all data, and thus become a so said "law of everything".[35]
The definition of personal data consists of four main building blocks: any information, relating, identified or identifiable, natural person. The definition on 'natural person' and 'any information' will be shortly summarized below whilst 'relating to' and 'identified or identifiable' will have their own subsections for explaining.

Personal data can only be gathered from natural persons, 'human beings', and thus the GDPR does not regulate data of legal persons. The natural person can be anywhere in the world for the GDPR to apply as along as the information is gathered in the Union.[36] So, in essence a natural person is a human being, a citizen of a state. The wording of any information is a very broad term. It literally encompasses all information from genetic, personal, political to for example banking details. Therefore, it is important to follow with the rest of the definition to give it its structure. The working party mentions that information that can relate to a person can take many forms. Alphabetical, numeral, geographical, photographical etc. even pictures drawn by someone is information.[37]To relate to the study matter of medical research, the wording of 'any information' is also very much present in research. The genetic and biometric data that is used in different studies is the backbone of that research and contains massive amounts of information. [38]

2.2. Relating to

The second building block of the definition is 'relating to', its purpose is to show the relationship between the information and the person it is linked to. Generally, data that relates to a person follows the simple rule that that information is literally about said person. [39] A name on a file probably is that individuals personal file.

An example, that was used by the working party to show the relationship of information and person, can be seen as a house that is sold on the market. The house itself does not seem to convey any personal data. But the information provided by the market value of said house can relate to the economy of an individual whose property it is. Thus, there is information and a relation to someone. But the wording of relating does not stop there. The relationship between

[35] Ibid, 41.
[36] Article 29 Working Party opinion 4/2007 on the concept of personal data, 20 June 2007, 21-22.
[37] Ibid, 7.
[38] Harbord, K. (2019). Genetic Data Privacy Solutions in the GDPR. Texas A&M Law Review, 7(1), 286.
[39] Purtova, N. (2018). The law of everything. Broad concept of personal data and future of EU data protection law. Law, innovation and technology, 10(1), 53.

information and person according to the opinion of the working party actuates that *"data relates to an individual if it refers to the identity, characteristics or behaviour of an individual or if such information is used to determine or influence the way in which that person is treated or evaluated".*[40]

Furthermore, the Working Party breaks up the wording of 'relating to' in three smaller elements, which give different context of relation to a person.[41] 'Content' being the first which is the most basic element. It describes the simple relation between content and person such as a file including a person's name. [42]This gives a straight relation between the file and the person whose name it is. The second element is 'purpose', if the information relating to the individual in question has the purpose of influencing or influencing the individual in any way taking into consideration all circumstances revolving around it. The third and last element is the 'result'. The third element can be defined as when the information has an impact on the individual's rights and interests. As the working party mentions the 'result' can be present where a person is treated differently based on the data that has been processed.[43] This means that the data does not have to focus on a specific person to sill have an impact and become personal data

The term 'relating to' is not discussed further in the GDPR. This makes it a term that must be understood as it is said. Information having a connection and relation with an individual. But it can be interpreted to have a very broad scope. All information that has any connection to an individual can be said to have a relation, however big or small, to an identified or identifiable natural person.[44]

2.3. Identified or identifiable

The third building block of personal data is the identifiers and identification, or as mentioned in the definition the "identified or identifiable". The reason it is mentioned twice is because there is a big difference in someone already identified by the data or someone who is identifiable.[45]

A person is identified if when gathered in a group of people that person is distinguishable from others. Another way of putting it is if the piece of information relating to a person is

[40] WP 105, 10107/05/EN, Working document on data protection issues related to RFID technology.
[41] Article 29 Working Party opinion 4/2007 on the concept of personal data, 20 June 2007, 10.
[42] Ibid, 10.
[43] Ibid, 11.
[44] Wong, B. (2019). Delimiting the concept of personal data after the GDPR. Cambridge University Press, Legal Studies, 39, 529.
[45] Article 29 Working Party opinion 4/2007 on the concept of personal data, 20 June 2007, 12.

distinguishable from other data. The identification is based on different identifiers that in ways separates data.

The other part of the building block, a person who is identifiable. This is a person who is not yet identified but by using the gathered data or collection of data it is reasonably possible to identify said person. The wording reasonably is important because almost anyone could otherwise be identifiable if all data possible would be available. But a reasonable person would not try to identify a person by searching through all possible data points. Identifiers are a key part identifying. It is the characteristics of the information that allows an individual to become identified. Possible identifiers to a person could be the individuals name, identification, length etc.

As the definition of personal data in the GDPR emphasises a natural person can be identified directly or indirectly.[46] The difference between the two is that being identified directly is by a simple immediate identification such as a person's name or date of birth. Different identifiers can be linked together to find a specific person easier. A very common surname is not a sufficient direct identifier such as Wong or Smith.
Then there are indirect identifiers such as identification numbers, passports or telephone numbers which depending on the context and available information can identify a person. Inherently you would not be able to identify a person by phone number solely, but by looking it up in a register you can find the identity.[47]

Identifiers are by themselves very valuable information, and even more so together. A study produced in the USA showed that only three identifiers were necessary to identify 87% of US residents. The three pieces of data being an individual's zip code, birth date, and sex.[48]

The major distinction between directly and indirectly is if you could point out that person by knowing the piece of information. A passport number would not allow you to point at the person strait away but would allow you to be able to find the name of the person, which makes is indirectly identifiable information.[49]

[46] Ibid, 13.
[47] Ibid, 13-14.
[48] Rumbold, J.M.M., Pierscionek, B. (2017). The effect of the General Data Protection regulation on Medical Research. J Med Internet Res, 19(2), 2.
[49] Ibid, 13.

2.4. The wide interpretation of personal data

The Article 29 Working party summarises their conclusion of their opinion on personal data as a possible warning. The wide interpretation that can be given to personal data and thus the data protection laws may end up applying to data in situations where it was not intended to be applied by the said rules and how the legislators saw it fit.[50] The argument that was brought up by the Working party is that vaguely, *everything is or contains information*.[51] So, if the relation and identifiability can be found through that information it would become personal data. This means that by a broad interpretation of the Article 29 Working Party's opinion on personal data it could be applied to everything that contains data.

The GDPR, following in the footsteps of its processor the DPD, also has the same style of writing of terminology in such an away to leave it quite open for interpretation such as "insofar as this is possible".[52] The reason for the wide style of writing is to make it possible for interpretations to be made in such cases where the regulation should be in effect. This also creates the problem that the opinion describes, where the definition of personal data is so wide that it could potentially include any information at all.

Personal data should in its essence be about data that is identifiable to said person. Even simpler, data that would allow a normal person to know who it is about without having to use complicated means to figure it out. But the implications the wide interpretation of personal data will allow is that personal data must be viewed in a wider spectrum. If analysed according to the opinion, it is not only about your name or location. It is about an individual's habits, bodily functions, opinions, and anything between. The possibility to characterise personal data only grows the more information something has. We must also take precautions not to overthink personal data. I am not trying to prove that a rock constitutes information relating to an individual but just open the mind for the spectrum of personal data.

[50] Ibid, 5.
[51] Purtova, N. (2018). The law of everything. Broad concept of personal data and future of EU data protection law. Law, innovation and technology, 10(1), 50.
[52] Lindqvist, J. (2018) New challenges to personal data processing agreements: is the GDPR fit to deal with contract, accountability and liability in a world of the Internet of Things? International Journal of Law and Information Technology, 26, 62.

3. MEDICAL REASERCH INFORMATION AND PERSONAL DATA

Medical research is quintessential to the development and to acquire new knowledge in the scientific health sector. It is the researching for new cures, how diseases spread, genetic information etc. all in all in encompasses a big variety of possible research in the medical and health field. But whenever there is a lot of researching in matters of health and medical science there is bound to be a vast amount of personal data involved.

Medical research can be finicky when it comes to personal data in the way that a lot of the information and research data is genetic or somehow related to persons. This means that even though it would be easiest to anonymise all the data used in medical research it sometimes is not possible to do so. Another impediment could be that individuals do not want to consent for research. Where's consent is the key to gather information.[53] Thea idea of giving consent for medical information can vary from person to person. People with rare diseases may want to give their consent freely for further development of that specific area. But then again people who do not gain anything from that research may not want to participate in it and thus making it harder to find data. One thing to remember that medical research is separate from normal medical procedures where identification is constant and normal. Where's medical research on the other have progresses through a larger quantity of information and thus many individuals.[54] Data is thus a prerequisite for research and to acquire new insight in the field of medical science.

The scope of what personal data the GDPR regulates has been mentioned earlier, but in the context of medical research it is crucial to take into consideration article 9(1) of the GDPR. *"Processing of personal data that reveals racial or ethnic origin,… genetic data, biometric data,… data concerning health… shall be prohibited"*.[55] This article as it stands would make it impossible to have any research done in the field of medical science where most of the personal data involved has genetic, biometric or health concerns involved. Genetic data can relate to DNA and the building blocks of each individual human being.[56] This encompasses health data about the individual by inheritance or self acquired, as well as any characteristics a person's health

[53] Rumbold, J.M.M., Pierscionek, B. (2017). The effect of the General Data Protection regulation on Medical Research. J Med Internet Res,19(2), 2.
[54] Bart, J., Jean, P. (2019). Medical research, Big Data and the need for privacy by design. Big Data & Society, 6(1), 4.
[55] Regulation (EU) 2016/679 of the European Parliament and of the Council of 27 April 2016 on the protection of natural persons with regard to the processing of personal data and on the free movement of such data, and repealing Directive 95/46/EC (General Data Protection regulation), published in Official Journal of the European Union, L 119, art 9(1)
[56] Harbord, K. (2019). Genetic Data Privacy Solutions in the GDPR. Texas A&M Law Review, 7(1), 269-296.

may have like diseases. Genetic data was not as well protected before the GPDR era, but several EU member states did include a greater level of protection to genetic data than to normal personal data.[57] Biometric data on the other hand can be explained simply with a finger. The finger itself is not biometric data, it is a tissue part which is genetic data. But the fingerprint is biometric data.[58] It is the different outside characteristics of the human body that makes biometric data, such as facial expression, retinal images etc. The Working Party 29 laid out the characteristic of how to recognise biometric data such as data that refers to biological properties, physiological characteristic, repeated action that are measurable. To simplify, any unique personal characteristic that can be individually identified.[59]Data concerning health or 'health data' is all the personal data that pertains to the health status of an individual and which can reveal personal information of the individuals present, future or past health status.[60] Past medical records would be the best example put forward when talking about health data. It is already recorded information that has a lot of information of a particular individual.

There is an exception to the article 9(1) on prohibited processing of personal data involved with genetic, biometric and health data. Article 9(2 j) allows the processing of data when the, *"processing is necessary for archiving purposes in the public interest, scientific or historical research purposes or statistical purposes in accordance with Article 89(1) based on Union or Member State law which shall be proportionate to the aim pursued, respect the essence of the right to data protection and provide for suitable and specific measures to safeguard the fundamental rights and the interests of the data subject."* [61] The article 9(1) states that personal data may be processed in scientific research purposes if there is a public interest for it. This statement could potentially make the hypothesis that data protection can have a negative effect on medical research obsolete, because we can assume that most medical research is done towards the public interest. This is not necessarily the case because of the high threshold European jurisprudence puts on the proof that the research is involved in something with larger impact and

[57] Vásquez, V.M. (2019) The protection of Genetic Data under the General Data Protection regulation. Datenschutz und Datensicherheit, 43, 154.
[58] Article 29 Working Party opinion 4/2007 on the concept of personal data, 20 June 2007, 9.
[59] Ibid, 8.
[60] Regulation (EU) 2016/679 of the European Parliament and of the Council of 27 April 2016 on the protection of natural persons with regard to the processing of personal data and on the free movement of such data, and repealing Directive 95/46/EC (General Data Protection regulation), published in Official Journal of the European Union, L 119, Recital 35.
[61] Regulation (EU) 2016/679 of the European Parliament and of the Council of 27 April 2016 on the protection of natural persons with regard to the processing of personal data and on the free movement of such data, and repealing Directive 95/46/EC (General Data Protection regulation), published in Official Journal of the European Union, L 119, 4 May 2016. Art 9(2j)

importance.[62] The derogation of rights cannot be taken lightly which could mean that researching alternative medicine that has no advantage over other products possibly does not meet the criteria of public interest.

3.1. Acquiring of data for medical research

Data used for research is acquired through explicit consent from data subjects when the data in question is identifiable.[63] That is why when it comes to research many tend to prefer data that has been anonymised to prevent a larger hassle. This sounds fine in theory, but even anonymised data has to be used in correct manners to avoid any bigger problems. It is not true that when data is anonymized the data controller and recipients are free from any obligations regarding the data. Even though the GDPR does not regulate anonymized data as mentioned before, the problem lies in the fact that anonymized data can become personal data again depending on how it is further processed.[64] An article on' genetic data in the GDPR' even suggested that when it comes to genetic data, it cannot be anonymized.[65] This is an important question because anonymization is a key feature for not including personal data in research.

Article 89 of the GDPR on *"safeguard and derogations relating to processing for archiving purposes in the public interest, scientific or historical research purposes or statistical purposes"*[66], which medical research could be argued to follow. The derogations in question are meant to prevent individuals of seriously impeding on valuable research, which is in the public interest.[67] This means that research which is not done in the so called 'public interest' does not constitute research which can derogate the rights of the Union citizens in the eyes of article 89. It falls down on the individuals conducting the research to either argue that it is in the public interest or follow more demanding requirements for anonymisation. [68]Pseudonymisation is a possible safeguard mentioned by the article which is how most medical research is processed. It

[62] Rumbold, J.M.M., Pierscionek, B. (2017). The effect of the General Data Protection regulation on Medical Research. J Med Internet Res,19(2), 2.
[63] Clarke, N., Vale, G., Reeves, E.P., Kirwan, M., Smith, D., Farrell, M., Hurl, G., McElvaney, N.G. (2019). GDPR: an impediment to research? Irish journal of Medical Science, 188, 1133.
[64] Stalla-Bourdillon, S., knight, A. (2016) Anonymous Data V. Personal Data – A False debate: An EU Perspective on Anonymization, Pseudonymization and Personal Data. Wisconsin International Law Journal, 34(2), 287-288.
[65] Harbord, K. (2019). Genetic Data Privacy Solutions in the GDPR. Texas A&M Law Review, 17(1), 272.
[66] Regulation (EU) 2016/679 of the European Parliament and of the Council of 27 April 2016 on the protection of natural persons with regard to the processing of personal data and on the free movement of such data, and repealing Directive 95/46/EC (General Data Protection regulation), published in Official Journal of the European Union, L 119, 4 May 2016. Art 89
[67] Rumbold, J.M.M., Pierscionek, B. (2017). The effect of the General Data Protection regulation on Medical Research. J Med Internet Res, 19(2), 3.
[68] Ibid.

is good to keep in mind that medical research is not the same as normal health clinic visits where personal data identification and collection is a normal daily routine, but it is the collecting of data for research purposes which requires deeper pseudonymisation efforts.[69]

The lawfulness of processing personal data according to the GDPR must follow drafted guidelines. There are six possible points of processing in article 6(1) of the GDPR of which there are a couple that would be regarded as preferred when conducting research. The first point of getting a hold of personal data for research would be data that has been consented to. The full and explicit consent of the data subject gives the right to process it further. It is good to keep in mind that a data subject may revoke said consent to different parts of research or wholly. The second point that was already mentioned is the processing for tasks carried out in public interest or official authority of the controller.[70]

A very topical data collection possibility which encompasses a lot of data is the so called Big Data, which is the result of recent technological advancements. The data is collected by multiple censors digitally that record every digital imprint a digital user may leave behind. This includes communications, movement and location, transactions and even data relating to an individual user's health.[71] The usage of Big data together with various software's may be the future of medical research when it comes to gathering data and analysing vast amounts of information. Salami. E. writes in his article AI, Big Data and the Protection of personal data in medical practice about how the usage of Artificial Intelligence together with Big Data can be the steppingstones needed to predict and diagnose diseases. The possibilities are for example predicting heart diseases in humans before any severe symptoms would arise.[72]

The implications that are obvious in Big Data when taking into consideration what has been mentioned before that information relating to individuals is personal data. This means that any information that could through computer software's give information of a particular individual is personal data and thus regulated by the GDPR. This implies that even though some strides could be made in medical research by just allowing AI's or software's to digest the information of Big

[69] Bart, J., Jean, P. (2019). Medical research, Big Data and the need for privacy by design. Big Data & Society, 6(1), 4.
[70] Regulation (EU) 2016/679 of the European Parliament and of the Council of 27 April 2016 on the protection of natural persons with regard to the processing of personal data and on the free movement of such data, and repealing Directive 95/46/EC (General Data Protection regulation), published in Official Journal of the European Union, L 119, Article 6.
[71] Zarsky, T.Z. (2017). Incompatible: The GDPR in the age of Big Data. Seton Hall Law Review, 47(4), 999.
[72] Salami, E. (2019). Al, Big Data and The Protection of Personal Data in Medical Practice. European Pharmaceutical Law Review (EPLR), 3(4), 166.

Data, it would still need heavy regulation by the GDPR. The individuals whose information is gathered has the right to know when their information is processed and to what means.

3.2. Restrictions the definition of personal data can have on medical research

So far it has been concluded that the article 29 working party opinion on personal data has given a wide interpretation on how much of all information is personal data. Now I want to focus on the question of how much could become personal data according to articles and the article 29 Working Party opinion. We, as humans gather vast amounts of data every day in data banks and by corporations like google, amazon, and other multibillion dollar corporations. Humans write about 3.5 billion google searches daily and send over 500.000 thousand comments every minute on social media.[73] These controllers of data have acquired the means and rights of their data subjects to collect and use their data as agreed upon. As Maria Tzanaou[74] and Bart J have written how data is collected and used by these corporations in means of creating profiles of people that they can allocate the correct data to.[75] But what some tend to overlook is the issue of the concept of personal data goes beyond simple identifiability, as written by Purtova. N. who is an associate professor at Tilburg institute of law. The relation of the data to a subject is broad and problematic as well.[76] Purtova discussed in her article "The law of everything. Broad concept of personal data and future of EU data protection law", how in a technologically evolving "on-life" world, everything will soon be personal data as interpreted by the article 29 Working Party opinion.[77]

The very interesting example brought up by the same article, is how weather for example in the future will become a part of personal data. How would this be possible, some can ask, but she puts it in good terms. Weather is a very natural phenomenon that is quite far away from what we would call personal data. There is of course data in weather, from moisture to rain density, how warm it is, etc. But there is no coherent personal data in weather itself.[78] The interesting idea is

[73] Tzanou, M. (2020). Health Data Privacy under the GDPR. London, Routledge 1st edition. Taylor & Francis group, 4.
[74] Ibid, 5.
[75] Bart, J., Jean, P. (2019). Medical research, Big Data and the need for privacy by design. Big Data & Society, 6(1), 2.
[76] Purtova, N. (2018). The law of everything. Broad concept of personal data and future of EU data protection law. Law, innovation and technology, 10(1), 42.
[77] Ibid, 78.
[78] Ibid, 57-58.

that in the future the gathering of weather information by different tools and sensors will collect so much data that in the sense of what the Article 29 Working Party described as personal data, the weather would also be a part of it. To remind of the definition of personal data "*any information relating to an identified or identifiable natural person…"*[79]. In this definition the information would not be about a natural person, but the weather information would be used for the purpose of influencing the behaviour of a person. Purpose being the second element of 'relating' where the data should influence the natural person in some way. This could mean that weather could influence a natural person's behaviour is some way which is the relation between the information and person. This kind of information can be used in research to assess the movement of citizens or individuals. But there is no identifying link between rainfall and the persons choice to not leave the house. Which makes the personal data definition obsolete.

Well not necessarily. The breakthrough case of Breyer v Bundesrepublik Deutschland was the first time the Court explicitly stated that all information needed for the identification of an individual does not have to be in the hands of a single person. [80]The information that was used as an example in the case of Breyer v Bundesrepublik Deutschland was if dynamic and static IP addresses could be deemed personal data. Static IP are personal data, but dynamic IPs alone cannot identify a person. If the dynamic IP is bundled with more information, it would be possible to identify someone through it, which makes it personal data.[81]Going back to the weather as personal data, if identifiable information does not only have to be gathered from one source but can be multiple sources of data together then weather could possibly be used in means of identifying a person which in turn makes it personal data. This must be observed with an open mind that in the definition the 'relating to' terms can be understood extremely broad. [82]

Now whether the broad definition of personal data can create difficulties when it comes to medical research, we must take a couple things in consideration. The problem can be structured in two points, firstly the applicability of the definition of personal data if viewed as the article 29 working party put it would mean that all data in the research could become personal data. The mere mention of a single data set could become the key to identifying a data subject in the

[79] Regulation (EU) 2016/679 of the European Parliament and of the Council of 27 April 2016 on the protection of natural persons with regard to the processing of personal data and on the free movement of such data, and repealing Directive 95/46/EC (General Data Protection regulation), published in Official Journal of the European Union, L 119, Article 4(1)
[80] Judgement of 19 October 2016, Patrick Breyer v. Bundesrepublik Deutschland, C-582/14, EU:C:2016:779.
[81] Borgesius, F.Z. (2017). The Breyer Case of the Court of Justice of the European Union: IP Addresses and the Personal Data Definition. Eur. Data Prot. L. Rev, 3(1), 130-137.
[82] Wong, B. (2019). Delimiting the concept of personal data after the GDPR. Cambridge University Press, Legal Studies, 39, 519.

research which in turn would turn the whole research into personal data, even though it would have been made from fully anonymized data samples. The question that comes to mind is what the effect would be if the research would become personal data. Sharing data is already an important perquisite when it comes to medical research and old research feed new ones. This is overall how we develop new theories and strategies, by analysing old data and creating new. But we must keep in mind that the importance when it comes to personal data is the rights of the data subject. The possibility to be identified with the relation to the research may not be in their best interest. Another thing to keep in mind is who will have access to the research, it would infringe the data subject rights if identifiable data on that person would be shared to third parties in disguise of anonymous data. Anonymized data as mentioned creates a false idea of not having the duties or precautions as when it comes to personal data.

This relates to the second point, where data not relating to a person or anonymized data can become personal data. This can happen by either the modernisation of technology or other sources of data revealing an identifying factor from the information. The recital 26 of the GDPR as mentioned before states the means reasonably likely to be used in identification takes into consideration the available technology at that time. Medical research is difficult with its sensitive nature of information, human tissues, biometrics, or medical records. This does not prevent medical research from using anonymized data or data from newly discovered formulas, that does not have any connection with an individual. But the problem arises with time when to these different substances of data some new additional information can be revealed which in turn gives an identifying factor relating to a natural person. Purtova. N. wrote in her article well about how different data collectors can have an effect which could even turn weather into personal data. This weather idea could be replaced with medical research and how the research may not inherently try to create information on a specific subject. The research could still potentially have an outcome that relates to an identifiable person.

CONCLUSION

The idea of the General Data Protection Regulation with its concludingly wide interpretation on Personal Data, becoming a regulation that has the effect of possibly encompassing all data into its scope is somewhat worrisome. Even the Article 29 working parties' opinion on the matter was that personal data is inherently too broad. The definition, which was broken down to the four building blocks, any information, relating, identified or identifiable, and natural person. It was a good idea to make the definition as broad as it can be interpreted now, but it is a double edged blade where the broad definition also allows other data to be included. The effect that the definition of personal data can have on medical research could possibly be a deceleration of research done.

The research question under what conditions medical research information can be restricted by the GDPR and fall under the definition of personal data as defined in the GDPR article 4(1) and the Article 29 Working Party's opinions, was discussed and analysed. The aim was not to prove that personal data is everything and anything in the world, merely to open the mind to the possibility that the definition for personal data can be objectively wide and that information, that inherently is not personal data, may unwillingly be regulated by the data protection regulation because of the broad definition of personal data as defined in the GDPR and with the opinions of the Article 29 Working Party on personal data. The different articles analysed give some insight in how the definition could affect different parts of scientific research, medical research in focus. The GDPR which only regulates the processing of personal data, data which can be attributed to an identifiable natural person, could influence medical research even after anonymisation or without any information relating to a person. Data that inherently is not personal data could become relating to a individual by combining it with data from another source. This is because personal data does not have to come from one source but can be from different sources, which together creates a data that relates to an identifiable natural person.

The data subjects have the right to consent and thus also not consent to data being processed about them. Here it is also important to keep in mind the data subjects right to remove any information pertaining to them. Medical research requires vast amounts of data to predict and conclude meaningful research. If individuals would demand the removal of data from a study, it could potentially slow down or even decimate the research of itself. People with diseases that would require more studying and research are usually more willing to participate and give consent to the further development for answers. But some people who do not see the effect of medical research on themselves using their own information can be more likely to deny consent

for the usage of their data.[83] Medical research does allow for some derogation of the data subjects right as long as it can be proven to be in the public interest. There must be a connection with pressing social need for the benefit of the public for research to use the exception of public interest.[84] It could be argued that most of the research done in the medical field is for the good of humankind, but that is an objective opinion up for scrutiny. The proof of the research being in the public interest still lies with the researchers to prove.[85]

The implications which a broad applicability of personal data can have on medical research is that the data protection regulation will be applied to cases where the data should be anonymized or not relating to a person. The information that can be gathered from any individual's data is not exhaustive because the possible information from data only grows with newer research technologies being adapted and with time.[86] This could allow the GDPR to become applicable to the medical research where identifying factors have been found, which in turn creates new steps to be taken to follow the data subjects' rights. This of course is with the idea that asking for consent and finding new data to replace the identifying data, would be the slowing effect. The GDPR of itself is not and should not be a burden for researchers. The only thing that would be worrisome for researchers is that the GDPR brings more responsibility and guidelines in how the data may be used. Researchers will have to be careful about information that could potentially lead to some sensitive identifiable data becoming published.

The topic of medical research potentially having negative side effect due to the interpretation of personal data is something that could have further, and deeper research made. It would be interesting to have some cases on this subject. Cases where the further study of the anonymized data in medical research would allow for identification of a natural person. This same research could be done with other fields of science in focus instead of medical. It could potentially show different albeit interesting results.

Social values must be defended when it comes to medical data. It is important to keep the persons integrity and privacy intact when conducting research work that has the power of

[83] Bart, J. Jean, P. (2019). Medical research, Big Data and the need for privacy by design. Big Data & Society, 6(1), 2.
[84] Rumbold, J.M.M., Pierscionek, B. (2017). The effect of the General Data Protection regulation on Medical Research. J Med Internet Res,19(2), 2.
[85] Regulation (EU) 2016/679 of the European Parliament and of the Council of 27 April 2016 on the protection of natural persons with regard to the processing of personal data and on the free movement of such data, and repealing Directive 95/46/EC (General Data Protection regulation), published in Official Journal of the European Union, L 119, 4 May 2016. Art 9(2j)
[86] Harbord, K. (2019). Genetic Data Privacy Solutions in the GDPR. Texas A&M Law Review, 7(1), 278.

identifying the data subjects used for the research. There is always potential confidential information that could be processed from data points even if they are anonymous, as long as the technology in research advances.[87] This reflects the extensive need of good and functioning personal data policies that not only supports the individual person but doesn't interfere with data that inherently is not personal data.

[87] Dumitrescu. R-M. (2018). Processing of personal and medical data by judicial institutions in the context of the enforcement of Regulation EU 2016/679 - General Data Protection Regulation (GDPR). Journal of comparative research in anthropology and sociology, 9(1), 16.

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