Children’s right to integrity - An analysis of children’s right to integrity in a patient support system

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Abstract

The thesis’ aim is to examine different aspects of the integrity of a child who uses a patient support system. The purpose and aim of a patient support system is to make it easier for the patients to get a better support in their daily struggle with their disease. The thesis will look and observe a patient support system Genia that aims at providing a tool for patients, foremost children, with Cystic Fibrosis. The thesis will shed a light onto the Swedish legislation regarding the legal criteria has to be fulfilled, different scenarios regarding responsibility of personal data and the child’s potential right to exclude parents from a certain function in the patient support system. The thesis will also look into how a provider and parents can contribute to uphold and strengthen the child’s integrity by giving the child privacy on the patient support system.
Abbreviations

WHO  World Health Organization
TF   Tryckfrihetsförordningen (1949:105) (Eng., The Freedom of the Press Act)
PUL  Personuppgiftslagen (1998:204) (Eng., The Personal Data Act)
FB   Föräldrabalk (1949:381) (Eng., The Parental Code)
PDL  Patientdatalagen (2008:335) (Eng., The Patient Data Act)
SOL  Socialjärnslag (2001:453) (Eng., The Social Services Act)
HSL  Hälso- och sjukvårdsagen (1982:763) (Eng., The Health and Medical Services Act)
OSL  Offentlighets- och sekretesslagen (2009:400) (Eng., The Public Access to Information and Secrecy Act)
LVU  Lag (1990:52) med särskilda bestämmelser om vård av unga (Eng., the Care of Young Persons (Special Provisions) Act)
UNCRC United Nations Convention on the Rights of the child
JO   Justitieombudsmannen (Eng., The Parliamentary Ombudsmen)
KES  Lag (2000:832) om kvalificerade elektroniska signaturer (Eng., The Electronic Signatures Act)
NIST National Institute of Standards and Technology
Prop. Proposition (Eng., Government bill)
SOU  Statens offentliga utredningar (Eng., Swedish Government Official Reports)
1 Introduction

1.1 Background

In the year 2015, it is evident that society, as a result of the social changes in recent years, is more than ever engaged in the advancement of technological devices. Internet, smartphones and Wi-Fi-devices are all digital communication technologies and have become part of the everyday life.\(^1\) The digital communications technologies have made it easier to interact and communicate with other people across the world. It has also been amplified into the world of fitness and exercise where popular apps, such as RunKeeper and MyFitnessPal Inc. have made fitness and health become more attractive and easily accessible, especially for non-athletes or those who are not regular gym goers.

A relatively new invention that can be found in all the new phones and tablets is the app. An app, abbreviation for application, is a piece of software, a program that can be downloaded on the smartphone and tablet, computer or other electronic devices.\(^2\) Thanks to the advancement of technology and the possibility to download apps, people are more interested in “health at home”, being updated on a daily basis and being involved in their health, but also gives individuals the possibility to contribute to their health situation. As a consequence of the new possibilities with apps, a shift in traditional care models has occurred, leading to new ways for patients, their doctors and carers to interact. There is a need for technology that can bridge health-related information through Internet and personalised eHealth applications that are based on mobile phones.\(^3\) There is reportedly a lot of literature on clinical apps and use of apps in areas of health wellness, but there is a lack of empirical analyses of

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1 The right to privacy in the digital age, p.1
2 Article 29 Data Protection Working Party, p. 4 & Encyclopaedia: Application
3 Boulos et. al., p. 1952-1953, 1968
patient using smartphones with app as an aid to facilitate adherence. However, there are a few studies that have shown that smartphones have improved patients’ health, for instance research about the improved health of patients with type 2 diabetes, and another about an app enabling empowerment of elderly in a nursing home. An app that serve as technical medical equipment that entails a higher risk, i.e. that provides with basis data to base a diagnosis on, is mandatory to CE mark and is regulated under Directive 93/68/EEC. The CE mark imposes a responsibility for the manufacturer and that it is safe to use if the instruction manual is followed. The popularity and the high potential of apps will most probably result in many more empirical studies in within the nearest future.

The usage of smartphones is today more accepted and even welcomed in clinical environments. The recognition of the smartphones and their capacity to assist in providing freestanding software, apps, to patients, strengthens their position as a health tool. A patient-driven health care service is emerging to supplement and extend traditional health care delivery models and can be defined accordingly:

“Patient-driven health care can be characterized as having an increased level of information flow, transparency, customization, collaboration and patient choice and responsibility-taking, as well as quantitative, predictive and preventive aspects.”

The patient-driven health care seems to be driven by patients and allow them to get a sense of empowerment, to gain power and capacity over their situation by increase patients influence and responsibility-taking. It will probably contribute to better healthcare since it aims at being more customized and focuses on the individual patient, so called patient-centered healthcare. There is a great poten-

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4 Dayer et al., p.172-181
5 Karolinska Institutet’s clinical research: Type 2 diabetes & Örebro University’s clinical research: App gives elderly empowerment
6 Council Directive 93/68/EEC Article 12 (1) and Article 15 (a) & The Swedish Association of Health Professionals on CE marking, p. 31-33
7 Medical Product Agency, p. 18-19 & Karolinska Institutet’s clinical research: Type 2 diabetes
8 Swan p. 512
tial for patient support systems to improve the health care system for chronically ill children and their families by making the patient feel better, enabling new ways for the professionals to learn new things about how it is to be a patient and the healthcare to be more effective. The shift to a more patient-focused and patient-influence healthcare is due to the view on patients’ role in the Western world has undergone a significant change over the years. We can see an ongoing movement towards the type of healthcare, which gives the patient a more active role in the relationship between patient and doctor.9

Genia, a patient support system is an app for patients, foremost children, with the chronic disease Cystic Fibrosis and their family. It aims to enable children and their families, the healthcare and other professions related to the treatment, to share useful information. The app aids the child and family to record their observations and challenges of the everyday life, such as the child’s psychological health, the healthcare at home, physical exercise, spirometric measurement and antibiotic intake. Patient support system can be described as technical service, via app or website, that provides several tools to support patient in their daily life by. Patient support systems can create a bridge between patient and care and it can do so more effectively through the use of Internet. By using cloud computing a provider can process information about the child over the Internet. NIST, an agency of the U.S. Department of Commerce, has defined cloud computing as a model that has five essential characteristics: on-demand, broad network access, recourse pooling, rapid elasticity and measured service.10

Patients who use patient support systems may at some point have to feed personal information into the service. The key words of the handling of personal information are: personal integrity (Swe., personlig integritet). The word integrity has evolved from the Latin word integritas, meaning untouched, whole.11 Integrity is associated with worth and dignity, which is every person’s inalienable right and it is a right that cannot be waived, not even by the person him-

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9 SOU 2013:2 p.76 & SNS: networks improve healthcare for patients with chronic diseases, p. 1-3  
10 NIST p. 2-3  
11 Encyclopaedia: Integrity
self. It also entails a right to decide what to do with information about oneself. The integrity could be violated or threatened in different ways. The right to keep some information to oneself is quite central in Section 1 PUL that states,

“The purpose of this Act is to protect people against the violation of their personal integrity by processing of personal data.”

Personal integrity is a central issue in patient support systems if information is collected or stored in their servers. Patient support systems and eHealth, a generic term for new service models within public healthcare that connects patient and provider through information technology, will most probably grow in the modern society and be a natural tool within the modern healthcare. Until then, it is vital and the responsibility of the provider of the patient support system to ensure that the child’s integrity is protected.

Genia has currently launched one version of the app for both children and parents/legal guardians to use. That means that both parents and children can access the platform for interaction and training diary called Genia Space, and participate and read the correspondence there. But not all children appreciate that parents are able to see what they write on the platform for interaction. The idea of the platform is to enable interaction and communication and the idea behind it is similar to Facebook and Twitter. As an interviewed child with Cystic Fibrosis said,

“It’s good that they [the parents] can see what I do and how I feel like in the tool “What’s up?” But I’d also like to be able to speak to other children and have little privacy in Genia Space. I don’t want them [the parents] to see everything.” - Leah, 11 years old.

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12 The Swedish National Council on Medical Ethics
13 The Data Inspection Board: Personal Data Act
14 Eysenbach
1.2 Purpose and research questions

With new technology comes great responsibility. A legal challenge with patient support systems is the child’s right to his or her own privacy and information. The integrity of a child who uses a patient support system, such as Genia, must be protected and there are several aspects of the integrity that is of concern. The aim of this thesis is therefore to elucidate and examine different questions concerning a child’s integrity in a patient support system.

The first question to be analysed is the legal criteria a provider of a patient support system fulfil to protect the integrity of a user. This question is important because of the personal data that is processed and it could be of very private and sensitive nature, i.e. concern the health status of a child. The personal data is most definitely a great concern of the child and the safeguarding of integrity. The integrity of children is of great concern from a legal aspect since they are a group that are unable to protect themselves and their integrity on their own, hence the importance that a provider of a system meet the criteria set by the legislator. It is also important to examine on what grounds a patient support system can fall outside the provision of the legislation that regulates process of individuals personal information. There may also be patient support systems that have a service where the user can send information to the healthcare. If such service is offered, when can the responsibility of personal information be shifted onto the healthcare?

With integrity comes the notion that one has the right to determine what information a person wants to share. Does a child have a right, and has it reached the level of maturity (Swe., mognadsgrad), to exclude parents from insight to and take part in a networking service, a platform for interaction? According to the Swedish Parental Code (FB), a child’s right to his other own integrity increases with age and maturity, but the legislator has not specified the age when the child upholds such right. The legislator has left it open to decide on when a child is mature enough, on an individual level.15 There is a possibility that a child in pre-teen years, age 9-14, does not want to share sensitive information

with parents. The need for wanting to keep some things to themselves depends on the child’s maturity and other factors, such as family relations. A child younger than 15 years old may feel that it has reached a level of maturity and therefore does not want to not disclose all the information to the parents. Of course, not all children want to exclude parents or feel they have the need to have the sort of privacy this thesis is discussing, but there are children such as Leah, see quote above, who would like to have some privacy, especially when they are on the threshold on becoming teenagers. But the question remains, is it possible for a child to withhold information, for example on Genia Space, from parents? A discussion will be held on if a child can uphold such right and an analogy will be made to the relatively strict healthcare legislation about the child’s right to integrity. The thesis will also discuss what parents and provider, of patient support system, can contribute to in giving children privacy, on for instance Genia Space, a platform for interaction.

The research questions are:

- What legal criteria must a provider of a patient support system fulfil to protect the integrity of a user?
- When can Section 6 PUL be applicable in patient support systems
- When can the healthcare be responsible for the information shared by a child through a patient support system?
- Does a child have a right to exclude parents from a platform for interaction in a patient support system?
- What can parents and a provider of patient support system do to ensure that a child get the privacy on a platform for interaction?
1.3 Method and Material

The thesis examines the questions in the light of a patient support system called Genia that will provide the reader with a better understanding of how the legislation is applied to the services of a patient support system in reality. Even though there will be a general discussion about the legislation and the responsibilities of processed personal data, it will also discuss it from Genia’s point of view and the services that the service offers.

The method used in the thesis is in Swedish called *rättsdogmatisk metod*, which is based upon the traditional legal method, where the essential issues are identified and analysed in accordance with the hierarchy of legal sources (*Swe.*, rättsskällläran).\(^\text{16}\) The current Swedish law and regulations in this field will be clarified and analyzed following the hierarchy of legal sources. Case law (*Swe.*, rättspraxis) on the area of child’s integrity with regards to patient support system is very little. However, there are a few decisions made by the Data Inspection Board, the authority appointed by the Government to perform supervision, on the usage of cloud computing and their inconsistency with Swedish legislation. Due to the lack of explicit case law, an analogy with the case law in the healthcare will be made that will show the challenges when deciding whose interest should be safeguarded in different situations, a child’s or parents’ interest. A comparison will be made with case law on the area of healthcare about to children’s right to integrity towards their parents.

Furthermore, the child’s right to integrity will be discussed on both an international and national level and it will lead to the discussion about whether or not a child can legally exclude parents from accessing Genia Space. This thesis will at the end of the thesis suggest ways for parents and provider to meet the child’s desire to exclude parents from Genia Space. It is important to distinguish between *de lege lata* (the legal position as it is) and *de lege ferenda* (the legal position as it ought to be).\(^\text{17}\) The suggestions are solely a result of my own thoughts and I am not by any means suggesting that this is how the legal

\(^{16}\) Kleineman p. 21

\(^{17}\) Kleineman p. 36
position ought to be. Nevertheless, I find it very interesting to discuss this issue and the suggestions will be based on ideas of consent, terms and conditions, and supervision of the platform. The analysis will be continuously carried out throughout the thesis and not presented in a chapter at the end of the thesis. The analysis will therefore be intertwined in every chapter.

The material used in the thesis is mainly traditional legal sources, however other sources will also be presented. The material used for this thesis will include both international and national sources. Articles from the United Nation’s Convention on the Rights of the Child that are relevant to the thesis will be presented. The thesis will also mention a Directive of the European Parliament and of the Council and case law from the European Court of Justice that discusses the process of personal data, and The European Commission work regarding strategies for the development of eHealth services.

As mentioned earlier, the thesis will follow the hierarchy of legal sources and when it comes to material it will follow the doctrine of traditional legal sources that keeps an order of precedence for the traditional legal sources (Swe., standardkällor). There will initially be an introduction of two of the four Constitutional Acts (Swe., grundlagar), the Freedom of the Press Act (TF) and the Fundamental Law of Freedom of Expression (YGL). After that an analysis of current and relevant legislation (Swe., lagstiftning), which consists of parliamentary acts (Swe., lagar) and government regulations (Swe., förordningar), will be held. Other important materials are the legislative preparatory works (Swe., förarbeten), because of their high degree of authority in the Swedish legal system and also, official letters (Swe., skrivelser) will be part of the thesis. The preparatory work is a unique and distinctive Swedish source that provides details that is missing in the statutory legislation. The courts and advocates often turn to the preparatory work to find an answer to a question or an issue that cannot be found in the legislation, doctrine etc. The preparatory works that are relevant in this thesis are related to a child’s integrity and the handling of personal data and helps us to understand the Government’s view on what the law is and what it ought to be.
The list of case law on the area of children’s integrity in patient support systems or apps in general, is very short and is almost non-existent. The few decisions that exists will be highlighted are made by the Data Inspection Board. It will therefore be difficult to find case law that says much about the questions of this thesis, which is why an analogy with the healthcare will be made. The purpose of the analogy is to identify and see the discussion regarding the child’s interest and integrity versus the parents’ right to insight to the child’s private life.

The last traditional legal source that will be used is legal scholarship (Swe., doktrin) that is an important source in Sweden hence, used by the courts. There will also be a large amount of digital sources because of the lack of clarified legislation (i.e. the child’s right to integrity increases with age, but when?), and case law on the subject.

1.4 Demarcation

The main focus of this paper will be the integrity of the child, but not all aspects can be covered in this thesis, and that is not the intention either. The aspects that will be the subject of the thesis will mostly be seen at from a child’s point of view but also the provider’s and parents’ when looking at parent’s consent and the safeguard measures a provider can contribute to.

Genia is collaborating with the healthcare and has developed a function where a child can send a pre-visit form, a PDF, with health-related information that is sent from the user. The pre-visit form can be sent to the clinic before the monthly or annual check-up and is used to make both patient and the professionals to be better prepared for the meeting at the clinic. It will briefly discuss the role of the healthcare, which is an important stakeholder, as a controller of personal data, and its legal responsibility in the scenario where a child sends a pre-visit form through Genia. It is interesting to examine the healthcare’s role as a controller of data and how the responsibility can be shared or even shift from a provider to the healthcare in different scenarios. However, the thesis will not go in-depth into this because the thesis does not have the healthcare’s
angle of vision. The healthcare will also be mentioned when the analogy is made between case law of healthcare and patient support systems run by private provider.

Furthermore, the other focus will be on the app’s the platform, Genia Space, and the possibility for children to have privacy there by excluding the parents from participating. The parents’ role and impact will be discussed when it comes to how the integrity of a child corresponds to their parental duty and further how the parents can contribute to the strengthening of the child’s integrity when consenting to being excluded hence giving the child the privacy on Genia Space. The provider’s point of view will also be discussed when writing policies and terms and conditions that contribute to the safeguard of the child’s integrity and the parents’ consent. Some relevant ethical perspectives are going to be discussed but to a limited extent. The ethical discussion obviously gives perspective to the question about the child’s right to privacy but it is not an exhausted explanation because the ethical issues are based on values and it is a matter of subjectivity.
2 Genia – a patient support system

2.1 eHealth

According to WHO, eHealth refers to the transfer of health resources and healthcare by electronic means.\textsuperscript{18} Both patient-driven healthcare and patient support systems derive from the idea to effectively transfer health resources. The meaning of the letter e, does not only stand for electronic, but it also entails different meanings, such as efficiency and enhanced quality, empowerment, encouragement and education.\textsuperscript{19} Not only could eHealth improve the use of health resources but also be used as a new medium for information dissemination and also for more effective way to interact and collaborate with other institutions, health professionals, health providers and the public.\textsuperscript{20} Not only will eHealth increase in efficiency due to reduced costs, but at the same time also by improving quality.\textsuperscript{21}

There is an international acknowledgement of eHealth and its opportunities to quality improvement within the healthcare and increase access.\textsuperscript{22} It has been recognised, not only in Sweden but also by the EU. The European Commission first eHealth Action Plan was adopted in 2004, and have since then has set up strategies for the development of eHealth services, The Directive on the Application of Patients' Rights in Cross Border Healthcare and its Article 14 establishing the eHealth Network, adopted in 2011, marked a further step towards formal cooperation on eHealth. The aim is to maximise social and economic benefits through interoperability and to implement eHealth systems. The response from the Member States has been dynamic and it shows that there is a high level of commitment to the eHealth policy agenda, i.e. through their par-

\textsuperscript{18} WHO & SOU 2006:82 p. 137
\textsuperscript{19} Eysenbach
\textsuperscript{20} WHO
\textsuperscript{21} Eysenbach
\textsuperscript{22} Ibid.
ticipation in major large-scale pilot projects.\textsuperscript{23} One of them being epSOS.\textsuperscript{24} Also, the WHO has adopted a resolution about eHealth where they urge member states to undertake long-term strategic plans for developing and implementing eHealth services in various areas of the health sector.\textsuperscript{25}

In Sweden, there is the Swedish National Strategy for eHealth that aims to adapt new ways of service deliveries within the Health and Social Care sector such as Mina Vårdkontakter (My health care contacts).\textsuperscript{26} It seems that patient support systems are welcomed and are seen as a new way to compliment the healthcare by making it more sufficient. By allowing patients to contribute and collaborate more with healthcare professionals we seem to move towards a more patient-centered healthcare. Genia, amongst other patient support systems are therefore very interesting for not only patients and the healthcare professionals that are on a micro-level but also on a macro-level, for the country and the EU.

\subsection{2.2 Cystic Fibrosis}

Cystic Fibrosis is a rare and life-shortening genetic disease caused by a gene mutation. Thick viscous secretions characterize the disease, which leads to a failure in the respiratory system to transport all of the mucus out of the lungs. The thick mucus that is left in the lungs cause a blockage of airways and result in coughs, shortness of breathe and frequent lung infections that are treated with antibiotics and other medications. There are also other symptoms affecting different parts of the body.\textsuperscript{27} There are approximately 670 patients with Cystic Fibrosis in Sweden, which equals to 7/100 000 citizens, and the number of children born with the disease is 20.\textsuperscript{28} A person with Cystic Fibrosis cannot

\begin{thebibliography}{9}
\bibitem{c1} European Commission p. 3
\bibitem{c2} EpSOS is a pilot project that came to an end in June 2014. It aimed to offer seamless healthcare to European citizens. The projects key goals were to improve the quality and safety of healthcare for citizens when travelling to another European country and focused on developing a practical eHealth framework and ICT infrastructure that enables secure access to patient health information among different European healthcare systems. \url{http://www.epsos.eu/home/about-epsos.html} [Accessed 8 January 2015].
\bibitem{c3} WHA58.28, Section 1, p.121
\bibitem{c4} Ejenäs p. 7, 9-10, Skr. 2005/06:139 p. 6-7 and My health care contacts
\bibitem{c5} Vårdguiden & The National Board of Health and Welfare: Cystic Fibrosis
\bibitem{c6} The National Board of Health and Welfare: Cystic Fibrosis
\end{thebibliography}
be cured; however there are several treatment methods that enable an individ-
ual with Cystic Fibrosis to live a fuller life and also to live longer than expected. The treatment puts a high demand on both the patient and his or her family. Self-management consists of respiratory and physical exercise, often perceived as burdensome, and can take up to two hours a day.  

\[2.2.1 \quad \text{Patient support system decrease risk of cross-infection}\]

For children with Cystic Fibrosis, cross-infection can be harmful and is therefore a threat to their health. Compared to other people, the individuals with Cystic Fibrosis are vulnerable to different bacteria or bugs that grow in their lungs. These bugs can easily be transmitted onto other people with Cystic Fibrosis, so called cross-infection. Due to the infection risk, they are advised to not to meet in person. For these children it means that they rarely can meet others with the same disease and same struggles and that is why patient support systems are great tools for them to interact and overcome the physical obstacles. Patient support system provides them with a platform for interaction from which they can share experiences and communicate with other children with Cystic Fibrosis.

\[2.3 \quad \text{Genia}\]

The care for a patient with chronic illness has for the last fifty years changed and the way of interaction has gone from fairly clear and simple between patients and professionals, to often quite complicated systems of care. There are approximately 670 patients who suffer from the chronic disease in Sweden. The app Genia is a patient support system, initiated by the Swedish company Chimes. The idea behind Genia is to enable patients and families living with Cystic Fibrosis, the healthcare professionals (Cystic Fibrosis-team) and other healthcare professions related to the treatment, to share useful health-related

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\[29 \text{ Vårdguiden & The National Board of Health and Welfare: Cystic Fibrosis}\]
\[30 \text{ Badlan p. 264-270}\]
\[31 \text{ Batalden et al., p. 549-551}\]
\[32 \text{ Kvalitetsregister}\]
information. Its purpose is to make the everyday life easier for patients, especially children who are bearers of this disease, and their families. The focus group of the app is children with Cystic Fibrosis and to provide them with an app that assists them in their management of their disease.

Genia consists of four functions: What’s up (a function that allows children to type in their mood and thoughts about their health), Medication (notes on medication), Notes and Genia Space. The app’s different functions enables children and family to record their observations and challenges of the everyday life, such as the children’s psychological health, the healthcare at home, physical exercise, spirometric measurement and antibiotic intake. One of the main functions of Genia is to facilitate collection and storage of personal data and observations to the healthcare professionals, prior to the appointed clinic visit, for instance with the help of pre-visit forms. The goal is to improve the monthly meetings at the Cystic Fibrosis clinic by helping healthcare professionals to be more informed about the patient’s health experience and to understand their situation. The provider of Genia has based the app on cloud computing. For a child to register for an account and for Genia to collects children’s personal information, Genia has to acquire parental consent because there is a thumb rule that a child under 15 is not capable of understanding the meaning of consent.33

2.4 Cloud computing

There are a lot of definitions on cloud computing. A search for it on the Internet will result in approximately 11 million results. NIST’s definition of cloud computing can be summarised as a model when needed (on-demand) to enable network access to a shared pool of configurable computing resources, for instance, networks, servers, storage, applications, and services. The recourses can then quickly be accessible and released with minimal management effort or service provider interaction.34

33 SOU 1997: 39 p. 279
34 Edvardsson et al., p. 21-22 & NIST p. 2-3
The provider of Genia has divided the service into two types of clouds, *private cloud* and *community cloud*. Some of the user’s information is collected and stored, and some is not. The infrastructure of the private cloud is provisioned for exclusive use and that use is reserved for registered user with an account. The private cloud is used as a personal account. It is organised, managed, owned and operated by Genia but it exist off premises meaning that Genia does not access or use information other than to do statistics, which users consent to. Other than that, Genia does not process any information in the personal account.\(^{35}\) The personal account is a private sphere on the Internet where the user can add notes and health-related information and is not shared with others unless the user approves of it. The private cloud can be compared to the idea of personal accounts on Dropbox or Evernote. The idea behind the personal account in patient support systems is interesting because the idea was presented in a pilot study called *Din journal på nätet* (Eng., Your Medical Records on the Net),\(^ {36}\) see chapter EHR-PHR.

The community cloud, on the other hand, is based on an infrastructure that is provisioned for exclusive use by a specific community. Children and parents share the same community cloud and use it exclusively, none other than users and Genia can enter it. The community cloud is open to users and allows Genia to access the information within the cloud. Genia Space is an example of a community cloud, with a specific community, that is all individuals who have registered for an account. The users of Genia Space share for instance the same security requirements and policy.\(^ {37}\) Its content is shared amongst others and is not like the information on the privacy cloud, where the only one who can see the content and store information is the user. Since the information in a community cloud is shared with others and also processed, i.e. when a child posts something or sends a message, Genia or more specifically the person responsible is for the handling of the private information. The information in Genia Space and the consented information that the provider has falls under the pro-

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\(^{35}\) See Chapter: Data storage  
\(^{36}\) *Din journal på nätet*: Final report  
\(^{37}\) Edvardsson *et al.*, p. 28-29 & NIST p. 2-3
vision of the person responsible for management of personal information on Genia.

2.5 Genia Space

Genia Space is the platform for interaction as well as a training diary and aims to support motivation to daily treatment. It is a platform under development and is inspired by social networks such as Facebook and Twitter, where communication and experience exchange are watchwords for meaningful meetings. The idea is to provide a platform for children where they can share thoughts, put up posts of training or daily life events and, share and communicate with others openly on a type of news feed, or through private messages. The communication on Genia is encrypted. In order for a person to access the app and its content, one would have to register an account and identify oneself with a username and password.

The provider has chosen to let some functions to be private, where the user is the only who can access the information such as the service, Medication. Other users such as parents may also access it, and there is a process for that but it will not be discussed in the thesis. There are also some functions where the information is shared in the open and in a community, such as Genia Space. On Genia Space, the users can write to each other, and in the nearest future perhaps post update status on news feed, and share things on a personal profile. Genia Space is a place for interaction and exchange. The provider has access to the information on Genia Space and is using and handling the information in different ways. Information is being handled for instance when a user writes to another user because the information that a user types into the platform is processed and then sent to the other user. Nonetheless, all process of data must be consented by users.

2.6 Data storage

A provider who has divided the app into a community cloud and a private cloud, where some information is for instance stored in servers and some in-
formation is not. The responsibility for the information is not always the providers or the person responsible for the app’s process of information.38 There is some personal information that will only be accessible to the user. The security of the information on a private cloud is dependent upon users and their private use of the security features on their smartphone. The health-related information, notes, medication etc. that a user feeds into the app can be classified as sensitive information and such information is stored in a personal account. The pre-visit form that includes information about the health can be sent from the private cloud. The pre-visit form is therefore not store the Genia. The provider only provides the user with the service to export the file and it is done the users personal account to the healthcare.

There is however information that is not only accessible by the user. According to Genia’s privacy policy, Genia is saving user’s username, email address and contact preferences to create and support the users Genia service account and to communicate with the user. They keep statistics on the user’s habits and what functions they use, for instance how many users use the tool Medication and how often. Of course, the provider must have the users consent to keep statistics on their habits. The information that the patient support system collects about habits cannot be traced to a specific user because the only thing that is shown is numbers and statistics. A user, whose information Genia collects to do statistics, is anonymous and can therefore not be identified. It is interesting to see how a patient support system can be structured and that there is a possibility to arrange the app so that a provider does not access information and hence, not be responsible for it being processed according to legislation.

38 See chapter 4, Legislation
3 Patient support system in collaboration with healthcare

3.1 EHR-PHR

The Swedish Government acknowledged the positive and potential outcomes from eHealth and initiated the National IT-strategy for healthcare (Swe., Nationella IT-strategin för vård och omsorg) in 2005 and 2006, presented in the Government Communication 2005/06:139. The initiative engaged all the Swedish City Councils (Swe., landsting) and they decided to establish a common action plan to adopt and implement the IT-strategy.

One of the goals of the IT-strategy is to provide patients with a platform in which patients could get accessibility and overview of his/her records, prescriptions and previous visits to the healthcare. This platform would also enable the patient to make notes in order to share them with the health professionals and to be able to trace others that took part of such information. In 2010, the IT-strategy was renamed and is now called National eHealth – the strategy for available and secure information within Health and Social Care (Swe., Nationell eHälsa - för tillgänglig och säker information inom vård och omsorg).

During 2011, Inera AB carried out the pilot study Din journal på nätet on behalf of CeHis, one many projects of the National eHealth. The aim for the pilot study was to elucidate opportunities for the health records to be made available for patients over the Internet and also to point out what ethical, medical and judicial consequences there are if health records where to be made available in such way. The pilot study Din journal på nätet showed that both healthcare professionals and patients express a need to communicate and interact electron-

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39 Socialdepartementet: Nationell eHälsa
40 SOU 2013:2 p. 327
41 Ibid. p. 327-328
42 Din journal på nätet: Delrapport 1, p. 3
ically within the healthcare.\textsuperscript{43} Even though the pilot study concentrates on investigat-
ing the need of a health account, managed by the healthcare, there are some interesting observations that can be discussed in the light of private pro-
viders of patient support systems.

The Patient Data Act (PDL) permits health professionals, mainly health pro-
viders, to provide a service where a patient can seek and read information via an account. The tool is often called “hitta och titta” (Eng., “find and see”) which in international terms is referred to as EHR – Electronic Health Record. The term EHR is often used for a system from which a patient can look at, but sometimes it refers solely to an electronic record system. While an EHR sys-

tem enables patients to seek and find information related to their health, there is no available system within the healthcare in which the patient can attain an active part of it by becoming a contributor to the health record. This was also affirmed in the pilot study where a conclusion was made that patients find that an EHR system is not sufficient in meeting the patients’ needs. The EHR sys-
tem is also not equipped to handle the challenges of the future healthcare.\textsuperscript{44} The patients are primarily asking for increased accessibility and better commu-
nication and more interaction, which also is beneficial for the process within the healthcare.\textsuperscript{45} The results of the study show that there is a demand by pa-
tients for a platform or a system that allows patients to contribute to their health and this ought to apply for children as well because they are very much involved in their health. The documented reaction and need for such platform is a visible plea of the patient to improve the information the healthcare uses as to support their decision-making.

The pilot project came up with a solution to the problem, called PHR– Personal Health Record that provides patients with a personal account. The PHR system allows the patients to add notes and medical on their personal account, through the Internet, and to contribute to their health improvement by having a more active role. It provides a more flexible platform, enabling patients to be more

\textsuperscript{43} Din journal på nätet: Delrapport 2, p. 27
\textsuperscript{44} Ibid p. 26-27
\textsuperscript{45} Din journal på nätet: Final report, p. 8
active and included in their healthcare that before. The PHR system enhances the patients’ elaboration with the healthcare, for instance by allowing the patients to participate in collecting and documenting useful information concerning their health. Genia is built and inspired by the PER system. The app enables users to add personal notes to their health-records, via pre-visit forms, or in other way contribute to their health documentation and quality of health care.

Since Genia is a limited company who uses such system PHR, a cloud service for its processing of personal data, the company is controller of the personal data. It is therefore the legal entity i.e. the limited company that will be held responsible if the company does not process the personal data in compliance with the Swedish regulations.

The care provider sends health-related information from Fack 1 to Fack 2, from which the information is sent to the receiver in Fack 4. The receiver is the patient and the information is sent to the patient’s personal account and cannot be

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Picture: Din journal på nätet: Remissunderlag, p. 12.

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46 Din journal på nätet: Delrapport 2, p. 7
47 See chapter 4, Legislation
accessed by healthcare. If a patient wants to send health-related information to
the health provider and the patient's own medical records (Fack 4), he or she
does so by sending it through Fack 3, which is an export surface. EHR and
PHR have both two separated accounts. While the EHR is regulated by PDL,
the PHR is not and is therefore subject to private providers who regulate the
service through contract law.

The model of EHR-PHR system can be a tool for providers of patient support
systems who want to collaborate with the healthcare. The information in a pa-
tient’s account (Fack 4) is neither shared nor accessible for the healthcare.
Since it is not processed or accessible to the health provider it cannot be a re-
sponsibility for such personal information (data). Genia has adopted the idea of
a PHR system by providing users with a personal account that has the same
concept as Fack 4, where Genia has no access to the users' information. The
personal account is detached from Genia and the community cloud, and is sole-
ly managed by the user/patient. Patient support systems that want to collabo-
rate with the healthcare and use the model EHR-PHR can provide with an export
and import surface from which health provider and patient can send infor-
mation back and forth.

3.2 Connection to the National eHealth Service System

The patient support system is connected to the healthcare system via the Na-
tional eHealth infrastructure. The flow of information between care provider
and user is today a pre-visit form with health-related information that is sent
from the user, similar to the EHR-PHR model. The pre-visit form and all the
information on it is on the user’s private cloud, also referred to personal ac-
count. It is not collected or stored by Genia. The pre-visit form must be struc-
tured in a certain way in order for it to be integrated with the National eHealth
service platform. Before information is sent to the healthcare system it has to
be authorised by patient or parents/legal guardians. It is done through a service
that fulfils the demands on encryption, authentication and validation. Users
must identify themselves with an electronic signature, such as Bank ID, to send
the pre-visit form to the healthcare. In Sweden, the majority of the Swedish banks use BankID, the leading electronic identification based on Public Key Infrastructure (PKI). It is an advanced signature and according to Swedish law and within the European Union, a signature with BankID is legally binding. As BankID is often used for digital identification as well as signing contracts and documents, it would be a proper way to identify oneself as a parent digitally and accordingly legitimatise the consent.48

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48 BankID
4 An analysis of current legislation

Providers of patient support systems may use the personal information a user is feeding into the system in order to assist patients, which often entails the handling of sensitive information about their health. The question is what measures the legislator wants a provider to take to safeguard the personal information, when the legislation is applicable and who is responsible for it. Also, it is vital to research on what legal position a child, including towards parents.

4.1 The provisions of PUL

When a person wants to register for an account in a patient support system, he or she has to register personal information, such as name, surname, address etc. The registered personal information is what PUL describes as personal data. The handling of a person’s personal data is regulated both on European level and national level. The implementation of PUL was introduced as a safeguard measure to protect individuals against the violation of their personal integrity when personal data is being processed (Section 1), and on the free movement of such data. However, there are a few exceptions and according to Section 7 PUL, the Act is not applicable if there is a collision with the constitutional protection for freedom of expression, contained in TF and YGL.\(^{49}\) PUL is based on Directive 95/46 of the European Parliament and of the Council of 24 October 1995.\(^{50}\) The Swedish courts and authorities are obliged, according to general principles of European Union law, to apply the law in accordance with the Directive and the interpretation of the European Court of Justice.

The process of personal data occurs when information about a user is used or managed. The term processed data implies collection, recording, organisation, storage, adaptation or alteration, retrieval, gathering, use, disclosure by transmission, dissemination or otherwise making information available, alignment or combination, blocking, erasure or destruction. The term process is applied to

\(^{49}\) SOU 2007:22 p. 433 & SOU 2004:114 p. 27

\(^{50}\) The Data Inspection Board: Personal Data Act
any operation/set of operations that are conducted with regards to personal data, regardless if it occurs by automatic means or not, Section 3 PUL. The description of personal data in PUL includes all kind of information that directly or indirectly that can be referred to a person who is alive. A provider often uses the information that is fed into the app by the registered user, and if that personal data is saved, collected or is stored; it is a process that fits PUL’s description. According to the Article 2(d) of Directive 95/46 and Section 3 PUL, a controller is the one who, alone or together with others, decides the purpose and means of processing personal data.51 Although the Article 2(d) of Directive 95/46 and SOU 1997:39 state that a controller could be a natural or legal person, the Data Inspection Board proclaims that the controller of the personal data is often a legal entity i.e. limited company or an administrative authority.52

There are a numbers of fundamental rules throughout PUL that a controller of must follow. The rules in Section 9 a-i is set out to guide the controller. For instance, personal data is processed only if it is lawful, (9a), personal data is only collected for specific, explicitly stated and justified purposes, (9c), no more personal data is processed than is necessary having regard to the purposes of the processing (9f). A controller is for instance permitted to turn personal data into statistics like the statistics used in Genia to monitor the users habits. In a Swedish Government Official Report53 it was concluded that information processed into figures and statistics is permitted if consent is given for the processed data and it does not mean that there is further intrusion into the personal integrity. Statistics could help a provider or controller of personal data to see how often the different functions of the app is used etc. and based on that, improve the app.

The Act only applies to those controllers of personal data who are established in Sweden and when the controller of personal data is established in a third country but uses equipment located in Sweden for the processing of personal

52 SOU 1997:39 p. 332, Directive 95/46 & The Data Inspection Board: The control of personal data
53 SOU 1997:39 p. 310
data, Section 4 PUL.\textsuperscript{54} This is quite essential when discussing whether or not a provider of a patient support system is obliged to follow Swedish regulations. The equipment probably is physical things and not acquired information from a database abroad. That means that support systems such as Genia that have their servers in Sweden are covered by the Act.\textsuperscript{55} There could be a scenario where a provider is based in a third country, for instance Bahamas, and that runs the app from there but have some sort of equipment in Sweden. However, a provider who is running the app from a third country and does not have any equipment in Sweden is also free and is not responsible for the processed personal data that is collected from Sweden. There are for example a lot of health-related apps, and other, that are not under the prevision of PUL because they are run from a third country even though people in Sweden download it and use it.

For a provider of a patient support system, whose audience includes or address children, the central concern is the process of the children’s personal data and information. The articles in PUL are mostly based on consent and adequate information to the registered individual.\textsuperscript{56} It is a fundamental right to be aware and approve of such actions that affect the registered person. For a provider such as Genia, it is vital to obtain the consent of users to use their personal data or fulfil the criteria in set out in Section 10 PUL. Consent is according to the Section 3 PUL, every kind of voluntary, specific and unambiguous expression of will by which the registered person, after having received information, accepts processing of personal data concerning him or her.\textsuperscript{57} Consent can only be valid if given by someone who is capable to understand the meaning and the consequences. A child under the age of 18 is eligible to give consent to processing of some personal data if he or she understands the meaning of such consent but it must also be consented by the parents.\textsuperscript{58} Depending on the maturity, age and the purpose of the processing of personal data, the parents’ consent may not be needed. The thumb rule is that a child over 15 is capable of

\textsuperscript{54} The Data Inspection Board: The Personal Data Act
\textsuperscript{55} Edvardsson et al., p. 101
\textsuperscript{57} The Data Inspection Board: The Personal Data Act
\textsuperscript{58} The Data Inspection Board: Consent
understanding the meaning and consequences of a given consent. The regulation is stricter when it comes to a child giving consent to historical, statistical or scientific purposes.\textsuperscript{59}

A failure or negligence to obtain consent, or meet the other criteria in Section 10, could result in the controller of personal data paying redress and compensation to the individual, Section 48 PUL. All the processed personal data through a patient support system must be handled according to the agreement and the user’s consent. It is not permitted to process information other than what it is agreed on and the legislator is very clear about it by imposing different legal actions against such act. The Act also mentions other forbidden actions that an individual takes that can lead him or her to be sentenced to fines or imprisonment, Section 49 PUL.\textsuperscript{60} An individual who undertakes illegal actions don’t necessarily have to be the controller of personal data, it could be a personal data representative, which according to Section 3 PUL, a natural person, appointed by the controller of personal data, who shall independently assure that the personal data is processed in a correct and lawful manner. The fact that the Act referrers to an individual and not a specific person, such as a controller, is vital because that means that a provider of patient support systems cannot delegate the tasks of process to someone else, a third party, and get away with breaching the law. According to Section 3 PUL, a third party is a person other than the registered person, the controller of personal data, the personal data representative, the personal data assistant and such persons who under the direct responsibility of the controller of personal data or the personal data assistant is authorised to process personal data. Sanctions may be imposed on some actions that an individual consciously undertakes knowing that the process is illicit, as well as someone who is unaware of it being illicit. The Government decided that it was legitimate to impose sanctions, fines and imprisonment, on some actions that were more serious, such as transferring personal data to a third country and illicit process of sensitive information.\textsuperscript{61}

\textsuperscript{59} SOU 1997: 39 p. 279
\textsuperscript{60} The Data Inspection Board: Consent
\textsuperscript{61} SOU 2004:6 p. 198
In recent years, the Data Inspection Board has been scrutinising the usage of cloud computing and found that many customers and providers of this type of IT-services, including counties, have failed to meet the legal requirements in PUL. In the last couple of years the Board has made several decisions against counties and a company for not arranging adequate safeguard measures to secure the user’s integrity. In December 2014, the Board made decisions against two Health apps, VaccBook and MinHälsobok (Eng., My Health Book), criticised their handling of personal integrity and the processing of personal data. The Board’s expressed concern is not unwarranted, since controllers of personal data deal with extra sensitive information and dealing with vulnerable client’s, both applicable on Genia. In the two decisions, it was stressed that the user must be provided with information about the identity of the controller of personal data, Section 25a PUL. It is very important for a user to know the person responsible for his or her information, hence The Board’s criticism on the lack of available information. The Board also criticised VaccBook for not having routines for erasing of personal data, Section 9i PUL, when the app was deleted. The Board referred to The Article 29 Working Party’s opinion on apps on smart devices, stating that app developers should predefine a time period of inactivity, after which the account will be treated as expired. It is also important that the user is aware of the timescale. The specific rules regulate different, and yet important questions regarding the process of personal data and even the handling of personal data after a user deletes his or her account. So far, it seems as if the legislation is able to cover the new challenges of patient support systems, apps etc.

The legislator has covered different subjects and specific matters that must be addressed to secure a persons information from being exploit and misused.

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62 The Data Inspection Board’s decisions against, Salems kommun (Salem County), Enköpings kommun (Enköping County), Sollentuna kommun (Sollentuna County) and företaget Brevo (the company Brevo)
63 VaccBook Dnr 1416-2013 & MinHälsobok Dnr 2059-2013
64 Article 29 Data Protection Working Party, p. 25
There is also sensitive information that a provider might deal with. It is noticeable that the legislation is stricter towards process of this type of information.

### 4.1.1 Sensitive information

When children or other group of patients with disease feed information into a patient support system, it could be sensitive information such as notes about medication, health and diagnosis. For a provider that collects information that is sensitive, it is vital to observe the legislation concerning such delicate matters. Section 13 PUL states that it is prohibited to process such personal data as concerns health or sex life. Nonetheless, several exemptions to the rule can be found in Section 14-20 PUL. Section 15 PUL states,

“*Sensitive personal data may be processed if the registered person has given his/her explicit consent to processing…*”

The legislation forbids information regarding health to be processed and used. However, the user’s consent can enable such process and can be required in order to create an account. The information about the consent must be shared with the individual before agreeing to the terms and conditions. The Data Inspection Board emphasizes the importance of information being clear and comprehensible. The information has to include contact information of the controller of the data, the purpose of the process of personal data and other details, such as, what type of data will be processed, to what companies or organisations may their personal data be handed out to, that the user has a right to demand an index or register to control what personal information has been registered. However, the user has the right to withdrawn his or her consent at any time, Section 12 PUL.

There is an exception to the provision of PUL, a loophole. A provider may be excluded from the provision of PUL as long as personal data is processed is of private nature, Section 6 PUL. If not, the provider is most likely to be a subject

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66 The Data Inspection Board: The Personal Data Act
67 The Data Inspection Board: Information to the registered
to PUL and further, has a notification duty according to Section 36 PUL. The controller of personal data shall provide a written notification to the supervisory authority, the Data Inspection Board, before the process is conducted.\textsuperscript{69} The provider is according to PUL is responsible for the process of personal data being in compliance with PUL and other Swedish regulations.

These issues are important to address for a provider that collects sensitive information. Since patient support systems aims at assisting patients in their daily struggle with disease-related issues, a provider ought to consider what type of information that is to be collected and processed. A provider could instead do like Genia, manage the app so that the sensitive information is fed into a private cloud where the user is the only one accessing it and the process purely personal.

\section*{4.1.2 Section 6 PUL - Operation of private nature}

The PHR system is based on a system supplied by a provider that is not a caregiver but a private supplier, usually a company. According to the final report of the pilot study Din journal på nätet, the handling of the account holder’s personal information, in a PHR system, is done within an operation of a private nature.\textsuperscript{70} The operation of private nature is an exception in Section 6 in PUL, preventing the Acts applicability, stating,

\begin{quote}
\textit{``This Act does not apply to such processing of personal data that a natural person performs in the course of activities of a purely private nature.''}\textsuperscript{71}
\end{quote}

The Article has the same meaning as the Directive’s Article 3(2) that the Directive shall not apply the processing of personal data, “by a natural person in the course of a purely personal or household activity”.\textsuperscript{72} Many comments have been made on Section 6 PUL, illustrating the aim and essence of the rule. Examples of activities of private nature are electronic diary and registration of family and relatives, also private correspondence via e-mail is considered to be

\begin{footnotesize}
\begin{itemize}
\item \textsuperscript{69} The Data Inspection Board: The Personal Data Act
\item \textsuperscript{70} Din journal på nätet: Final report, p. 9
\item \textsuperscript{71} The Data Inspection Board: The Personal Data Act
\item \textsuperscript{72} Directive 95/46/EC, Chapter I General Provisions, Article 3(2)
\end{itemize}
\end{footnotesize}
an exception. The European Court of Justice has ruled on the matter of the definition of processing of personal data and further that was seen as an exception to the Directive. In the case C-101/01-Lindqvist, the European Court of Justice stated that the exception only applies to activities carried out in the course of private or family life of individuals and not to processing of personal data that consist in publication on the Internet, enabling indefinite number of people to access those data. The process of personal data, that a person process or keep of private nature, is therefore excluded from the implementation of the PUL.

A system such as PHR could be excluded from the implementation of PUL since it is not applicable on an individual who handles the personal information, where the processing personal data is of private nature. This is correct as long as the provider of such a system does not collect personal data. Recently, the Data Inspection Board decided that Gravidappen, a pregnancy app, did not fall under PUL since they found that the personal data is stored in their personal account and the company does not have access to the information. When the user erases the account, all personal data stored in the app is automatically erased. The Board compared it to an electronic diary, notes solely for private use and decided that the process of personal data was of private nature, Section 6 PUL. Genia has written in their privacy policy that certain information about the user that will be collected for different purposes. The controller of personal data is therefore responsible for the information that is processed, but not for the users process of his or her own personal information. The users information such as notes on medication, documentations etc. is processed in their personal account. The controller of personal data has no access to a user’s personal data making the user the only one who is able to access his or her personal data, with exception to the collection for statistics that is based on consent. This way, all the personal data is stored in a private account, as described in the pilot study and seen in the Data Inspection Board’s decision about Gravidappen, is seen as a digital diary, making it a process of personal

73 Karnov: a comment on Section 6 PUL
74 Case C-101/01, Section 47
75 Din journal på nätet: Final report, p. 18, 23
76 Gravidappen Dnr 1451-2013, p. 2
data of private nature Section 6 PUL. A provider who provides personal accounts to users and don’t process the information is no of no legal concern to a provider since that information is not within the controller of patient data’s scope of responsibility.

4.2 Shared personal data with the healthcare

PDL primarily regulates the processing of personal data within the health and medical services, and applies to all care providers. For instance, it regulates internal secrecy and electronic access within a care provider’s operation, the disclosure of documents and data through direct access or by other electronic means, national and regional quality register and addresses the obligation for the carers to keep patient records. The regulation is a part of an ongoing process to enable, through the aid of IT, better communication between the stakeholders within the health and medical care services but also to improve carers’ patient orientation.\(^77\)

Once the care provider has handed over information to the patient, often in paper, the PDL no longer regulates it. The information is considered to be the patient’s property and the care provider have no longer control over how the patient uses that information, whether or not it is shared with others. This ought to apply for electronic information as well. The legislation does not regulate the type of service where patients can add notes.\(^78\) A private provider, not a care provider, provides Genia and that is why it is excluded from the provision of PDL.\(^79\) Genia’s account has an export interface to which a pre-visit form can be sent by the user and received by the care provider. The pre-visit form contains specified and structured information that can be saved as an entry in the patient’s medical records.\(^80\) The question is who is responsible for the processed personal data when it is sent to the healthcare, the provider or both, and when this personal data is a legal concern of the care provider. Even though this will not be discussed in depth, it is interesting to see the information ex-

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\(^{77}\) SOU 2006:82 p. 35-36  
\(^{78}\) Din journal på nätet: Final report, p. 9  
\(^{79}\) Ibid. p. 26  
\(^{80}\) Ibid. p. 9
change and how it affects the responsibility of the controller. It is most probable that the care provider will be responsible for the patient’s personal data leading to such information being a subject put under the scope of PDL, Section 3. At some point the caregiver will process the pre-visit form. Depending on if the provider of a patient support system stores personal data, the provider could be responsible for it after the user sends it. In Genia’s case, the pre-visit form is set up in the personal account and is not stored by Genia and hence, not a controller of it.

The care provider would probably have to undertake certain safeguard measures before receiving the pre-visit form, for instance a security service that fulfils demands of encryption and validation of the patient by electronic identification, such as BankID.\textsuperscript{81} It is likely that a private provider might offer such security measures. The same demand for security service would apply, according to the new PDL, if a care provider hands out information to the patient over the Internet, i.e. to their Genia account.

The healthcare will most probably offer more services over the Internet, such as patient support systems or other services provided by the healthcare itself. Patients’ information that is sent to and from the health care is very sensitive and therefore crucial to structure the process in such way that it will not violate patients’ integrity.

\textbf{4.3 The Parental Code}

According to Chapter 3, Section 1 FB, a child has a right to be maintained and protected by its parents. Both doctrine and preparatory work stress that it entails to get ones physical, i.e. right to a adequate livelihood, and psychological needs met such as right to safety, stability and, having someone to depend upon and trust.\textsuperscript{82}

The ambition for this thesis is to discuss the children’s right to their integrity, not only towards a provider and third party, but also towards parents. There is

\textsuperscript{81} The Patient Data Act and personal integrity
\textsuperscript{82} Schiratzki (2013) p. 59
not a specific regulation in FB regarding the children’s usage of patient support systems. However, since Genia is dealing with health issues and handles sensitive information, it is of great concern to the parents who according to Chapter 6, Section 1 FB, have a parental duty to be the child’s care givers. The parental duty entails raising and educating a child into adulthood and foremost, providing the child with nursing care throughout their childhood. A child’s usage of the platform for interaction on Genia is arguably a matter of importance for parents, and thus, the discussion regarding the parent’s approval is central. A child who is younger than 15 years will probably have to get their parents consent to such service. As mentioned earlier, the Data Inspection Board has stated that a child is mature enough to give consent to the processing of his or her personal data at the age of 15.83

Even though the parents, as care givers, have great impact on a child and are responsible for their care, the legislation has also acknowledged the child’s opinion and will. It stated in the second sentence of Section 11 of Chapter 6 FB, that a child’s right to integrity increases with age and maturity. This means that a child has a right to be heard in matters that concern them given that they have developed a sense of integrity. According to comments made on The second sentence of Section 11 of Chapter 6 FB, the Act does not clearly state at what age a child has reached such a maturity and to what extent a child’s opinion and will ought to weigh in, in personal matters. The question is when a child have a right to exclude parents from taking part of sensitive information on Genia and whether or not a child between the age of 9 – 14 has reached such age and maturity as implied by the Act.

**4.4 Children’s ability to attain privacy through contract law**

There are numbers of legal situations where the child’s rights and opinion is more stressed than others, i.e. when deciding joint custody and access to children, during an investigation regarding child abuse by the social services

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83 The Data Inspection Board: Consent
(Chapter 1, Section 2 SOL), and in the interaction between the healthcare professionals and a child (Section 2g HSL). When looking at children rights on a national level, we’ll shortly discover that they often lie in the division between civil law and public law. The division between civil law and public law is very interesting to analyse and is somewhat central when discussing how a child using a patient support system can claim the rights to privacy on Genia Space. Can a child become a contracting party when agreeing to the terms of Genia? Swedish legislation says that a child under the age of 18 has no legal competence to make such commitments and undertake obligations, although there are some exceptions. It is generally up to the parents to make such a decision and entering contract on behalf of the child.

While the child’s encounter with healthcare is regulated under public law, the child’s rights concerning i.e. entering of an agreement concern his capacity to contract, and thus is regulated by civil law.\textsuperscript{84} A child has \textit{legal capacity}, but not full \textit{legal competence}. Every physical person, from the moment it is born until it dies, is recognised as an \textit{entity}, allowing the individual to own property, have debts etc. An entity has legal capacity, making it possible to have rights and obligations and the ability to be a part of a judicial process (\textit{Swe.}, partshabilitet), not to be confused with legal competence. The general rule is that an individual with legal capacity also has full legal competence, but a child has not since it is a minor. A nine-year old has legal capacity to own a house, but not the ability to perform i.e. to sell or accept the house as a gift, due to the lack legal competence. A child has no legal right to undertake obligations on its own. But the older the children gets the more legal capacity is given and by the age of sixteen, the legal competence give them the ability to manage their own salary, Chapter 9, Section 3 FB.\textsuperscript{85} This is why a child cannot agree on the terms and conditions and become a party of an agreement by a provider on their own, the parents must agree on behalf of a child. A child could agree to the terms and conditions but there can be no consequences for the child if it breaches a contract. Why would this be important? If a child who uses a patient support system wants to protect his or her personal integrity by keeping certain

\textsuperscript{84} Schiratzki (2014) p. 19
\textsuperscript{85} Ramberg p. 54-56
information private from parents, it is vital to examine if a child could achieve that on its own through contract law. In Sweden, it would not be probable since the target group of children in this thesis are at the ages of 9-14. The age limit might change in the future, as the children get more used to Internet-based services at an early age and have better understanding of such services. Even though it is a rule of thumb, the child will probably not have the legal capacity to consent to a providers terms and conditions that allows the child to have privacy in the app and thus, the privacy achieved by a child, aged 9-14, through contract law is not probable. Privacy can only be achieved through parents’ interference.
5 Children’s right to integrity

Nowadays, children are exposed to the Internet more than ever, making them accustomed to communication through Internet-based services, and users of social media and apps at a young age. Children in the Western World are born in a time where the Internet is a big part of society and social life. Through social media, sites or apps to connect with other people, such as Facebook, Twitter and Instagram, the users, including children, are connecting with together people around the globe through a personal profile. It is space that is considered to be a private sphere, a personal account that is displaying parts of ones private life.

Genia Space allows a digital space where children can chat with other children. It provides platform that enables connection to others that have the same struggle in life, where they can share experiences and motivate one another. The freedom to express and communicate with others sometimes includes some privacy from parents. From a child’s perspective, it can important to have a little space of privacy, especially when talking and sharing experience and emotions with other children who many times have had the similar challenges. The question is if a child has the right to hinder parents from using Genia Space?

5.1 Children’s rights

For more than a quarter of a century, the United Nations Convention on the Rights of the Child (UNCRC) has, on a global scale, influenced, changed and shaped children’s rights and living conditions all over the world. The convention is somewhat of a ‘Northern star’ for the world’s countries, a guiding-star for the goal and major task of securing and guaranteeing the child’s rights on a global scale. The convention is according to UNICEF the most rapidly and widely ratified international human rights treaty in history.\(^{86}\) There are current-
ly 194 countries that are parties to the treaty, all UN members, except for Somalia and America that has yet to ratify it. Ever since the UN Convention on the Rights of the Child (UNCRC) was ratified in Sweden in 1990, the efforts of underlining and bringing forth the child’s rights in legal areas, including their right to their own integrity, have been more intense and the work unceasing. In a letter to the Parliament, the Government revealed how it intends to continue to pursue the strategic work of the implementation. Also, the Swedish Parliamentary Ombudsman for Children have been given a key role in pursuing the implementation, including monitoring the compliance, of the UNCRC. The definition of a child, in Article 1 UNCRC, is not an entirely exhausting rule since it refers to domestic law and allows member states to intervene with their own definition of a child.

“For the purposes of the present Convention, a child means every human being below the age of eighteen years unless under the law applicable to the child, majority is attained earlier.”

The general rule, according to Swedish legislation, is that a child stops being a child the day he or she turns eighteen years old. The child’s rights are in some legal areas stronger than others because it is seen as more important to preserve. The third Article UNCRC state,

“The best interests of children must be the primary concern in making decisions that may affect them. All adults should do what is best for children. When adults make decisions, they should think about how their decisions will affect children. This particularly applies to budget, policy and law makers. “

The third Article UNCRC primarily points at the measures taken by the states government because it is the Government and its bodies that are constrained by the Convention. However, the Article should also apply to parents. The parents should think about the how their decision would affect the children and to

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87 Ewerlöf et al., p. 22
88 Skr. 2003/04:47
89 UNCRC Article 1
90 UNCRC Article 18 & Schiratzki (2013) p. 76-77
do what is best for them according to Article 18 UNCRC.\textsuperscript{91} The child’s best is a legal ambition that has central for a decision to meet the child’s different needs and interests.\textsuperscript{92} Children who wish to have some privacy and the desire to have a private sphere on a patient support system is most definitely something that parents must consider and take into account.

The child’s best interest is also defined on a national level. However, the notion and opinion on what a child’s right is differs from one legal area to another. Also, the diversity is shown in the implementation and prospect to argument for children’s right in different areas of the law.\textsuperscript{93} For instance the pre-work of LVU state that a child is to be regarded as an independent from parents and other family members.\textsuperscript{94} As previously mentioned, a child aged 9-14 will probably not have the right according to Swedish law to enter contract and agreeing to terms and conditions that allows a child to have that privacy through contract law. Instead, the child’s right to integrity will be examined through public law, mainly FB. FB is quite central since it regulates children’s right to integrity towards parents.

5.2 Children’s right to integrity increases with age and maturity

Children’s right to integrity in national Swedish legislation is foremost regulated in FB which states that the child has the right to its integrity and that is vital in order for a child to learn to make his or her own decisions, the child must get a fair chance to influence his or her own situation and the parents ought to encourage the child’s ability and will to express his or her wishes. However, it does not mean that parents always have to practise children’s expressed wish and will.\textsuperscript{95} Also, parents should not give the child the right to make all the

\textsuperscript{91} UNCRC Article 18
\textsuperscript{92} Singer p. 34
\textsuperscript{93} Schiratzki (2014) p. 36
\textsuperscript{94} Schiratzki (2014) p. 34
\textsuperscript{95} Olsen p. 185
decisions.⁹⁶

The parental duty, which is regulated throughout FB, continues until the day that the child turns 18, Chapter 6, Section 2 FB. It is also the parental duty that justifies their right of determination (Swe., bestämmanderätt) over a child.⁹⁷ Parents have the right to represent the child in matters where that representation is not specifically regulated by legislation, such as representation by social services according LVU, i.e. Section 6.⁹⁸ Children’s right to self-determination and the ability to act independent is limited.⁹⁹

According to the first sentence of Section 11 of Chapter 6 FB, the parental duty presumes that parents have an insight to the child’s life and business.¹⁰⁰ The legislator has at the same time clarified that children have a right to their own integrity and that parents must recognise their opinion and wishes, which is interpreted as a child’s right to co-determination.¹⁰¹ The influence of a child in the family is regulated in the second sentence of Section 11 of Chapter 6 FB and is based on general principles. The general principles have no great legal significance other than bestowing a long-term impact on parents and legal guardians.¹⁰² Even though it has not the legal significance as with other regulations, the parents a responsibility for the child and includes making decisions based on what’s best for the child, Article 18 UNCRC is the central point of UNCRC.¹⁰³

According to the second sentence of Section 11 of Chapter 6 FB, a child’s right to integrity increases with age. Although the Act states that the child has the right to integrity as they develop but age is not defined in the Act, hence the uncertainty of at what age child has the right to integrity. However it does not eliminate the parent’s obligation towards the child and, to provide and protect the child. At the same time the regulation states that a child’s right to integrity

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⁹⁶ Ewerlöf et al., p. 31
⁹⁷ Schiratzki (2013) p. 77
⁹⁸ Schiratzki (2013) p. 53, 78
⁹⁹ Schiratzki (2013) p. 51
¹⁰¹ Schiratzki (2013) p. 61
¹⁰² Prop. 1981/82:168 p. 88
¹⁰³ Söderbäck p. 130
must increase with age and maturity. As a child grows and matures, they develop a need for liberating itself from the parents. Children’s liberation from the parents could mean having their own space, to make their own decisions and parents granting them an appropriate degree of privacy. The liberation is crucial step towards becoming an independent individual, hence the importance of the parents acceptance of it. The legislator not established a certain age of when a child has reached “the right age” and that is why the question of maturity must be decided on an individual basis. In theory, the will of a child could in some aspects be in a conflict with the parental duty. The complexity of balancing and handling these interests are vital when developing a patient support system that focus on children and in creating a platform from where children can interact and communicate with other individuals with the same disease.

Although Swedish legislation clearly states that a child has a right to integrity and also manifested Articles throughout UNCRC, the right is not hands-on because it is too vague and unclear. The legislation cannot answer the question on when a child is mature enough to have the right to integrity. Since there is not much guidance in the legislation and, case law regarding patient support systems and the issue about children’s right to integrity is almost non-existent, the thesis will look at past decisions and case law on healthcare. Even if the resemblance is not great between, the children’s whish to exclude parents from insight and information in patient support system and the healthcare, it is nonetheless, interesting to see at what age a child is considered to have attained maturity. Although a service such as Genia Space does not necessarily have to do with health-related information, even though children may discuss health-related issues it with other children, the healthcare and its case law can shed a light onto children as co-decision makers and their self determination which in this thesis is viewed as part of their integrity.

104 Ewerlöf et al., p. 31
5.3 Analogy between healthcare and patient support system

Given that there is not much guidance in case law to be found in this area, an analogy with the healthcare and its case law is at hand. The analogy aims at elucidate problems that occur and the complexity of the child’s will and co-decision right but also the pursuit of implementing the child’s rights into healthcare. Even though the case law will not cover the scenario where a child wants to keep some information to itself in a patient support system, it will be interesting to see how the conflict between children’s and parents’ will is discussed and what case law has brought with into this field.

When the law is unclear, children’s need of protection and support may not be met and furthermore that their integrity will be violated. The uncertainty of the legislation regarding when a child is mature is also noticeable within healthcare. In an earlier Government bill, the former Government shed a light onto the challenging conflict between the parental duty and the right to the child’s own integrity, affirming that the parental right decreases as the child gets older. In healthcare, it means i.e. that the parents cannot always access the child’s health records that are confidential without the child’s consent.

A report in 2008 addressed to the Parliament by the Swedish National Council on Medical Ethics (Swe., Statens medicinsk-etiska råd), pointed out in that the rights of children, as patients, are almost invisible in current legislation that is governing the healthcare. This has caused the Government to commence a research and discuss the issue in, for example prop. 2013/14:106, the new Patient Data Act that came into force 1st of January 2015. The Government bill on the Patient Data Act has shed a light onto the questions regarding children’s rights to integrity, including their right to self-determination and as co-decision makers, and also the protection of their integrity. Depending on the type of procedure and the situation, and maturity, a child can decide to commence a

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106 Söderbäck p.14
107 Prop. 1988/89:67 p. 36-37
108 Skr. Children’s position within healthcare
procedure on its own even though the healthcare professionals are advised on striving towards making parents involved. Weakness of integrity is a consequence of children’s limited self-determination.

In a Government Official Report concerning patients’ judicial position, it was stated that parents normally have the right to make decisions in issues that are related to a child’s personal matter, which is referring to the parental right in FB. Nevertheless, when a child has reached a certain level of maturity but is not considered adequate or competent enough to make decisions, consent is needed from both child and parents. The problem of deciding at what age a child reaches the level of maturity to make own decisions has to do with the risk of making children undertake great responsibility when they are not mature enough, whilst other children can be refused the right self determination regarding decisions they are mature enough to make. To decide an age for when a child’s reaches maturity within healthcare is very complicated. It is stressed once again, in a recent Government bill that the level of maturity is individual and differs from one child to another. However, the Data Inspection Board’s rule of thumb, that a 15 year old has reached that level of maturity, is also shared with the Government.

The healthcare deals not only with at what age the child reaches maturity and all issues related to that but there is also a difference between a child’s positive bestämmanderätt (Eng., positive right of determination), the right to apply for a procedure, and negativ bestämmanderätt (Eng., negative right of determination), that a child alternatives to a certain procedure are cut down to two. Even though different types of right to determination have not been discussed, it is worth mentioning to give an idea of the questions complexity the health providers has to deal with.

109 Prop. 2013/14:106 p. 63-66
110 Bischofberger p. 39
111 SOU 1997:154 p. 60-61
114 Svensson p. 871 & Schiratzki (2013) p. 60
5.3.1  **Case law**

It seems to be somewhat problematic to draw the line between the child’s right to its own integrity, right to self-determination and co-determination, and the parents’ obligation and right to raise the child.\(^\text{115}\) There is an immense risk for division between a child’s wish and sense of integrity and the parental duty, which presumes a right to insight into a child’s business, which often leads to demarcation problems.\(^\text{116}\) This difficulty is shown more explicit in case law where issues regarding children’s will and integrity are in conflict with the parents will and right to insight into the child’s privacy. The decisions on whether or not the healthcare to waive the confidentiality of a child, seem to depend on different variables.\(^\text{117}\) Sensitive information of a child could be kept confidential if there is an assumption that the child will suffer significantly if such information is disclosed to the parents, Chapter 12, Section 3 clause 1 OSL. It is not enough to keep information confidential from parents if a child thinks that the parents will undertake certain measures that the child does not approve of or that a child finds it unpleasant if the information is to be disclosed to the parents.\(^\text{118}\)

The Parliamentary Ombudsmen (JO) has in a decision\(^\text{119}\) spoken out about the prescription of contraceptive pills to a thirteen-year-old girl. JO stated that it would hardly be reasonable to demand to inform the parents or legal guardian when a seventeen-year-old wishes to get contraceptive pills prescribed to her. A seventeen-year-old child is considered to have reached that level of maturity FB describes, but not a thirteen year old. A child at the age of 13 is not considered mature enough to deal with a decision and the consequences of taking contraceptive pills. It would considered to appropriate to inform the parents so that they parents can address with issue with her.\(^\text{120}\)

\(^{115}\) Schiratzki (2013) p. 60-61
\(^{117}\) Prop. 1998/99 p. 468
\(^{119}\) JO 1992/93 p. 439 f.
\(^{120}\) JO 1992/93 p. 441-442 & Socialstyrelsen, Nr. 7/2010 p. 2
According to a statement in a Government bill, children who reach their teens have reached the level of maturity and ought to have some protection of their integrity towards parents. But Socialstyrelsen (Eng., the National Board of Health and Welfare) objects to parents being deprived of such information that is important in order for them to fulfil their parental duty and to provide for the child.

Another sensitive situation is when a child, under the age of 15, gets pregnant. The Swedish abortion law does not set a minimum age for abortion; it only says that a woman have a right to do it, Section 1 (Abortlag (1974:595)). In theory, a child can have an abortion but, as in the case with the contraceptive pills, it conflicts with the parental right to insight into the child’s privacy. JO criticised the school of an 11-year-old girl who got pregnant for not disclosing information about the matter to the Social Services. An 11-year-old child is obviously not mature enough to understand the consequences of abortion on her own. Jo also commented on the matter of the absence of age in the Abortion Act, stating that absence of age regulation does not mean that authority can neglect the child’s age.

Case law does not bring enough clarity as to when a child is mature enough to have the right to their own integrity and the right to decide on matters. It does not give clear guidance on when a child has reached an age where the right to integrity is obtained. Nonetheless, the level of maturity of a child seems to depend on different variables such as the age, matter of subject, the procedure and the consequences of a decision. However, the case law does not address questions outside the healthcare and nevertheless, a provider of a patient support system. To simply apply the reasoning and thinking within healthcare directly on the situation that might emerge between a child and parents regarding a patient support system, when discussing exclusion from a platform for interaction, is neither optimal nor satisfactory. It does, however, shed a light on a complicated issue and the difficulty to draw the line between a child’s right to

121 Prop. 1988/89:67 p. 36
122 Prop. 1998/99 p. 468
integrity and parents’ right to insight. Case law on this area has shown that a child’s interest, will and right to integrity will not always outweigh the parental duty.

5.4 Children’s ability to exclude parents on legal grounds

The decisions made by JO,\textsuperscript{125} are guidelines but it is important to remember that children’s maturity must be determined individually because children’s situation and circumstances may differ from one another. The case law illustrates that there are some health related matters children don’t want to share with parents, but rather wanting to keep it private. The legislation and the Government bill\textsuperscript{126} aims at describing the healthcare and the professional’s role and how they, according to law, must work with children. During the pre-work for the new Patient Act that came in to force 1\textsuperscript{st} January 2015, the Government discussed the rights of the child within the healthcare that would be affected, and proposed ways on how to be more aware when encountering a child and how to implement the child’s right into the Act in a more effective way.\textsuperscript{127} We can see that the consciousness towards the child’s best and will still continues and can be seen in government bills, regulations, policies and guidelines.

Due to the fact that Genia Space is not connected to healthcare professionals and not directly to healthcare, the case law cannot apply directly to the child’s privacy on Genia Space. A child’s wish and need to exclude parents from the Genia Space to have some privacy would perhaps be compared to keeping a diary or letters of correspondence with friends and not wanting parents to read it. The law does not give a child the right to stop parents from participating and have an insight to a child’s life, including a platform for interaction that is not connected to healthcare. It is not likely that the legislator wants to protect the child’s integrity to this level, and forbid parents from reading diary or letters. To go as far as to say that a parent has no right to read conversations a child

\textsuperscript{126} Prop. 1988/89:67
\textsuperscript{127} Prop. 2013/14:106
has with together children or hinder them to get insight to the child’s private life, including digital private space, would not be a rational conclusion. There has to be more at stake to waive the parents’ right to insight into the child’s private life other than simply reading a child’s thoughts and correspondence on the chat. The prohibition of the parents’ insight could be possible if crime has been committed and the social services take away the child and put it into foster care. That way, the parents could loose their parental duty. Even though a child has the right of co-determination and the UNCRC states that a child’s voice and will should be heard and be taken into consideration when parents are making decisions, to say that a child has the right to exclude parents from a platform for interaction or networking service is not probable. Even though a child has reached an age where it is considered to be mature and thus, have the right to integrity, it would not mean that the child has a right to exclude parents from insight to a platform for interaction, such as Genia Space. The child’s wish to privacy would probably not be a right that the legislator finds is worth to preserving. However, their will and wish should be seen as children’s plea and has to be taken under consideration. If there is no legal ground for the child to proclaim its rights to privacy towards the parent, can the parents and the provider do something to give the child the private sphere?
6 Parents and provider’s collaboration

Although a child cannot exclude parents from Genia Space, perhaps the parents and the provider could arrange something to establish privacy on the platform. Parents could agree to give children private space by giving consent to the provider not to have the app version that includes Genia Space but register for an alternative version where Genia Space is not accessible. This would mean that provider and parents could collaborate, and the provider can present safeguard measures to meet the parents’ need for securing children and to strengthen children’s right to their integrity.

6.1 Children’s need for privacy

Today, children use social networking websites and apps more than ever and create their own profiles. Social media offer platforms through which interaction can take place, such as Facebook, Instagram and Twitter but they often have age restrictions. Facebook, amongst other apps and sites, requires that a user must be at least 13 years old before creating an account. A survey conducted by the Swedish Media Council showed that 68 % of the children in the survey aged 9-13, had Facebook-accounts. The percentage was even higher for older children aged 13–16 and the results showed that 96 % had Facebook-accounts. A recent report was conducted by OfCom on behalf of the UK Communications Act 2003 on the media use on children in the UK and it showed a lower frequency use compared to Swedish children. Only 28% of 9-10 year olds had social networking profiles and 59% for 11-12 year olds. The report also suggests that the age limit that has been set out by the apps and sites, such as 13, is not followed in reality. The children under 13 years create fake accounts by lying about their age in order to access the networking services.

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128 Facebook: report a child under 13
129 Swedish Media Council: Youngsters and media, p. 9, 42
130 Media use and attitude reports 2014, p. 8, 21
There are certain risks involved when children create fake accounts on Facebook and other apps and sites, because they have not reached the age limit. Parents’ may worry about children being bullied, exposed, taken advantage of, grooming, self-harm and suicide-related content.\textsuperscript{131} A child is most likely to share very sensitive and private information, such as photos, phone numbers and address, and falls for group pressure that inflicts bad influence on the child.\textsuperscript{132} Not only does parents need to know that their children use Facebook but also understand and talk to the children about the dangers on social media. It is not unlikely that children hide the fake accounts from their parents. If children create fake accounts to interact with others, then surely we can see that there is a need for interaction, and social media seems to be our modern tool for it. The creating of fake accounts could also point towards a desire to create a space where a child can communicate with friends and discuss things through i.e. chats or by sending private messages. But desire to interact is perhaps even more for children with Cystic Fibrosis who cannot meet up with other children who have gotten the same diagnose because of risk of cross infection.

In a study, carried out by Palmer & Boisen in 2002, the participants, who had Cystic Fibrosis, reported that they felt that they had to avoid certain places and environments, making them feel that it constrained their social life.\textsuperscript{133} Their life is in some way limited as to where to go and who to meet because of their disease. Since patients with Cystic Fibrosis seem to feel that their social life is constrained, a patient support system with a networking service, such as Genia Space, could provide with a community in which they can “meet”, interact with others and find support. The study indicates that the patients are missing out on some parts of the social life and that is a key factor to why patients’ support systems could play a part in tomorrow’s modern healthcare. The opportunity to communicate with other patients, share experiences, daily struggles and encourage one another would seem to be beneficial to them. The digital meeting with other children with could contribute to a lot of things, i.e. motivation, advise on training and treatment, support in their daily struggles in

\begin{flushleft}
\textsuperscript{131} The Guardian  \\
\textsuperscript{132} Forbes  \\
\textsuperscript{133} Palmer p. 45-58
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schools, with friends and family and nonetheless, other children’s behaviour towards the child. There are also experiences and situations a child goes through that are sensitive to a child, for instance that they feel different or cannot do the things other children do due to their disease. This is sensitive information and it is important to give children, especially when they are reaching their teens, their space to share these experiences and situations with others. Children may not always want to talk about awkward questions or experiences with their parents but rather with a friend that has gone or is going through the same thing. That is why it would be proper for parents to give a child that space in the open by agreeing to it and giving the provider their consent to be excluded from Genia Space. This way a child has the parents’ consent that is based on trust, understanding and openness.

6.2 Parents’ consent

The privacy could be granted to the children by the parents’ who give their consent to it. The provider can through a type of policy-making gather the parents’ consent by getting their approval of the terms and conditions when they first register for a Genia-account. The consent would amount in parents using another version of Genia that does not contain the function Genia Space and hence wont get the insight to the child’s activity on Genia Space. Parents would probably legitimatise their consent for instance with an electronic signature, such as BankID. By doing so, the parent can give their consent to the provider to give the child another version that includes Genia Space. Besides agreeing to the child having one version and the parents another, the parents, on the behalf of the child, also agrees to the process of the child’s personal data on Genia Space. This is done even regardless because to process the personal data of a child, under 15 years of age, the parents would have to give consent to it. As with the information collected when first creating an account, the user’s personal data in the community cloud Genia Space is processed, making it the responsibility of the controller of personal data. As mentioned earlier, consent can be withdrawn at any time, Section 12 PUL.
Even though there are no legal actions for the child to take on when a parent withdraws the consent, there is a widely acknowledged principal called til-litsprincipen (Eng., principle of trust), which most probably is the common ground on which the consent is given. Presumably, both parties, child and parents, want to give the child the privacy and that is an indication of parents interest in keeping the agreement. This type of agreement could be described as one that is built on trust and other social factors, such as the relationship between a child and its parents, which might be of an immense emotional value. Based on the relationship and the trust that is at stake, the agreement between parents and child, although none binding in legal sense, could very well accomplish the wanted effect: to keep the agreement. Although the principle is only recognised as a guideline, it could have the cultural and social impact on the agreement and amount in parents not withdraw their consent unless the there is a suspicion that the child’s well-being is at risk. However, parents would presumably want to ensure their children’s safety and want reassurance that the children wont be bullied, exposed etc. The provider could meet the parents’ distress and request by establishing safeguard measures to secure the child’s integrity and safety on Genia Space.

6.3 Provider’s safeguard measures

There is no legislation that stipulates that a provider must specifically have the interest of the child in mind but in reality, a company whose focus group is a child will have the child’s best interest to reach and attract its target group. A company who provides a patient support system for and wants children to use it but will not adapt the service to the children would probably not be as successful. A way of establishing the privacy a child wants in Genia Space has to, as mentioned in previous chapter, involve a child’s parents. The provider could write the terms and conditions in such way that it includes parents’ approval and consent to let the provider manage privacy for a child on Genia Space if the child and parents wants to. Even though not every child wants this kind of privacy from its parents this could be a solution for those children who do want some privacy.
As previously mentioned, the provider could launch an alternative version of Genia for the parents without the Genia Space-function. However, it is presumable that all parents’ want safety of their child and would probably feel distressed not to have an access, insight, to the child’s activity on Genia Space. There are several apps, such as the app Mamabear,\textsuperscript{134} that focus on this issue about the parents’ insight to the child’s activity on social networking apps and sites. The app enables parents to monitor the child’s activity, for instance on Facebook, to ensure safety.\textsuperscript{135} Although the thesis is not focusing on parents monitoring the child directly, the need for reassurance of the child’s safety and well-being on Genia Space could be achieved in a different way.

The provider of the patient support system can implement safeguard measures to ensure children’s security and integrity. To give the parents the assurance of the child’s safety, the provider could introduce a policy document that the child must agree to follow to be able to use Genia Space. The policy can be described as code of conducts or rules where certain rules of behaviour are stressed and has to be followed by the users in the virtual community. The child’s approval of the policy does not have any legal significance other than to follow social rules such as, not allowed to: bully anyone, use strong language etc. By accepting the policy in Genia Space, the child is obliged to follow the rules. To implement the rules and to get the children to participate and approve of the policy, the provider could do interviews with the children at the clinics or through questionnaire. The policy could perhaps even be the result that is solely based on thoughts and inputs by the children.

Another safeguard measure to ensure the integrity of children and decrease the risk of harm is through a type of supervision. The question of responsibility of supervision of Genia Space is a great challenge. The provider could accommodate the service with a moderator to ensure that the policy that the community has approved of is being followed. This would however not mean that it would override the controller’s responsibility of the information according to PUL.

\textsuperscript{134}Mamabear
\textsuperscript{135}Forbes
The controller would still process information in the community cloud and be held responsible according to PUL. The provider could introduce a safeguard measure for both parents and child by supplying Genia Space with a moderator, also called admin. The moderator could be an older person with Cystic Fibrosis, perhaps an older teen who is mature to take on the responsibility of monitoring, that supervises the service and who gives warning or excluding a child if it breaks the rules. The moderator would be monitoring on voluntarily basis. This idea could be compared to a closed Facebook group where admin has set out the terms of joining the group and allows him or her to exclude a member that is not following the rules. The monitoring of the children’s private messages is not that easy and would not be possible.

The provider’s safeguard measures, policy and supervision, and the collaboration with parents can be a solution in giving children the requested privacy on Genia Space.
Summary

Healthcare is now facing an era where new technology that can lead to new learning, take a natural place in the everyday life. It is a movement towards giving patients a more active role in their recovery and/or daily care of their disease.¹³⁶ That includes new inventions such as patient support systems for patients with the need to monitor their health. In dealing with patients, especially children and information that is health-related and sensitive, the questions about their integrity are of great importance. The questions in the thesis are quite important to examine and comprehend because a child’s integrity has several aspects to it.

A provider of a patient support system must fulfil the requirements set in the legislation regarding the personal data about a user that is processed. Both Directive 95/46 and PUL, along with Government bills and Swedish Government Official Reports, states that there is responsibility for handling personal data, for instance through a patient support system. PUL addresses the responsibility to a controller of personal in Section 3 PUL that is the one who decides the purpose and means of processing personal data.¹³⁷ There are a numbers of fundamental rules in Section 9 a-i, to guide the controller of personal data, and also other criteria stated in PUL for a controller of personal data to follow and adapt to. A patient support system that has the same structure as Genia, divided into two models and uses the concept of a private account, where the user is the only one who can access the information through private cloud, is probably excluded from the provision of the PUL. This is due to information is saved in the private cloud and is seen as a process of private nature Section 6 PUL resulting in the controller of personal data not being responsible for that process of personal data. On the other hand, personal information that is processed, such as the community cloud Genia Space, is a responsibility of the controller. The responsibility can also be shifted onto healthcare if information from a user is sent to a care provider.

¹³⁶ SOU 2013:2, p. 76
¹³⁷ SOU 1997:39 p. 333
The children today can download a lot of social networking apps such as Instagram, Facebook and Twitter and many of the children are creating fake accounts because of the age limits that are set by the social networks. Children seem to have the need to be on social media and communicating with others. The interaction with others is perhaps even more important for children with Cystic Fibrosis because of the risks involved in meeting others with the same disease. A patient support system with a platform for interaction with others in the same position could be a good tool for virtual meetings. There is a possibility that children from the ages 9-14 have developed a sense of integrity and maturity and wants to have some privacy when it comes to issues related to their health. Although the Parental Code states in second sentence of Section 11 of Chapter 6 FB states that a child’s right to integrity increases with age and maturity, the legislator has not defined at what age a child reaches that level of maturity. There is therefore no profound legal ground on which a child can stand and claim its right to integrity. The uncertainty of the timing of a child’s integrity seem to be blur even within the healthcare.

Case law is lacking in the area of patient support systems but in the area of healthcare, it has shown that there can be division between the child's wish and sense of integrity and the parental duty that presumes a right to insight into the child’s business. The different interests regarding disclosure of a child’s health records to parents seem to be evaluated, and a decision on disclosure is made depending on the seriousness and the risk of a disclosure harming a child. The probability for a child to have a right to exclude parents from functions on a patient support system such as Genia Space is minimal. It would most probably be compared to a child having a right to prevent parents from reading its diary. However, the thesis suggests an alternative to give a child that kind of privacy and it entails collaboration between parents and provider.

In order to meet some children’s need and desire to privacy in Genia Space a solutions could be to establish an agreement between the parents and the child based on a mutual understanding of the privacy, assisted by a provider. Parents

can give their consent to a provider to exclude them from using the same version of the app as the child that includes Genia Space. The provider would instead launch an alternative version of Genia for the parents without the platform. A provider, who has parents’ consent, can offer the safeguard measures: policy and supervision. There would be a moderator who supervises the platform and the children’s activity on Genia Space.

As children mature and are exposed to a virtual world where social networking play a natural part of their daily life, it is vital to address their request for privacy, but foremost to find a solution. The safeguard measures are not given solutions but a result of answers to the questions, how to make it possible for children to get some privacy and how it can be achieved with the help of parents and provider. Generally speaking, it is better to communicate and for children to be open with their parents than the opposite and that is why the thesis is discussing the parents’ role. Even though this idea might not be the best solution or that it has many flaws, it is nevertheless a stepping-stone. To come up with a suggestion and to try to apply it to a real situation is all part of learning and coming one step closer to the right solution. This is my small contribution to it. Perhaps the children of tomorrow and parents will have a better understanding of social networking and have more experience in coping with issues related to privacy. It is even possible that safeguard measures wont be relevant in the future and that legislation is more clear and detailed regarding children’s right to privacy in patient support systems. Until then, we ought to emaine and address questions that involve the integrity of children with diseases, who are extra vulnerable individuals, when using patient support systems. The new wave of patient- driven health care is on our doorstep, and it seems it is here to stay.
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Directive
Directive 95/46/EC on 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.

**Encyclopaedia**


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Abstract

The thesis’ aim is to examine different aspects of the integrity of a child who uses a patient support system. The purpose and aim of a patient support system is to make it easier for the patients to get a better support in their daily struggle with their disease. The thesis will look and observe a patient support system Genia that aims at providing a tool for patients, foremost children, with Cystic Fibrosis. The thesis will shed a light onto the Swedish legislation regarding the legal criteria has to be fulfilled, different scenarios regarding responsibility of personal data and the child’s potential right to exclude parents from a certain function in the patient support system. The thesis will also look into how a provider and parents can contribute to uphold and strengthen the child’s integrity by giving the child privacy on the patient support system.
### Abbreviations

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
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<tbody>
<tr>
<td>WHO</td>
<td>World Health Organization</td>
</tr>
<tr>
<td>TF</td>
<td>Tryckfrihetsförordningen (1949:105) (Eng., The Freedom of the Press Act)</td>
</tr>
<tr>
<td>PUL</td>
<td>Personuppgiftslagen (1998:204) (Eng., The Personal Data Act)</td>
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<tr>
<td>FB</td>
<td>Föräldrabalk (1949:381) (Eng., The Parental Code)</td>
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<tr>
<td>PDL</td>
<td>Patientdatalagen (2008:335) (Eng., The Patient Data Act)</td>
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<tr>
<td>SOL</td>
<td>Socialtjänstlag (2001:453) (Eng., The Social Services Act)</td>
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<tr>
<td>HSL</td>
<td>Hälso- och sjukvårds lag (1982:763) (Eng., The Health and Medical Services Act)</td>
</tr>
<tr>
<td>OSL</td>
<td>Offentlighets- och sekretesslag (2009:400) (Eng., The Public Access to Information and Secrecy Act)</td>
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<tr>
<td>LVU</td>
<td>Lag (1990:52) med särskilda bestämmelser om vård av unga (Eng., the Care of Young Persons (Special Provisions) Act)</td>
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<tr>
<td>UNCRC</td>
<td>United Nations Convention on the Rights of the child</td>
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<tr>
<td>JO</td>
<td>Justitieombudsmannen (Eng., The Parliamentary Ombudsmen)</td>
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<tr>
<td>KES</td>
<td>Lag (2000:832) om kvalificerade elektroniska signaturer (Eng., The Electronic Signatures Act)</td>
</tr>
<tr>
<td>NIST</td>
<td>National Institute of Standards and Technology</td>
</tr>
<tr>
<td>Prop.</td>
<td>Proposition (Eng., Government bill)</td>
</tr>
<tr>
<td>SOU</td>
<td>Statens offentliga utredningar (Eng., Swedish Government Official Reports)</td>
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1 Introduction

1.1 Background

In the year 2015, it is evident that society, as a result of the social changes in recent years, is more than ever engaged in the advancement of technological devices. Internet, smartphones and Wi-Fi-devices are all digital communication technologies and have become part of the everyday life.\(^1\) The digital communications technologies have made it easier to interact and communicate with other people across the world. It has also been amplified into the world of fitness and exercise where popular apps, such as RunKeeper and MyFitnessPal Inc. have made fitness and health become more attractive and easily accessible, especially for non-athletes or those who are not regular gym goers.

A relatively new invention that can be found in all the new phones and tablets is the app. An app, abbreviation for application, is a piece of software, a program that can be downloaded on the smartphone and tablet, computer or other electronic devices.\(^2\) Thanks to the advancement of technology and the possibility to download apps, people are more interested in “health at home”, being updated on a daily basis and being involved in their health, but also gives individuals the possibility to contribute to their health situation. As a consequence of the new possibilities with apps, a shift in traditional care models has occurred, leading to new ways for patients, their doctors and carers to interact. There is a need for technology that can bridge health-related information through Internet and personalised eHealth applications that are based on mobile phones.\(^3\) There is reportedly a lot of literature on clinical apps and use of apps in areas of health wellness, but there is a lack of empirical analyses of

\(^1\) The right to privacy in the digital age, p.1
\(^2\) Article 29 Data Protection Working Party, p. 4 & Encyclopaedia: Application
\(^3\) Boulos et. al., p. 1952-1953, 1968
patient using smartphones with app as an aid to facilitate adherence.\(^4\) However, there are a few studies that have shown that smartphones have improved patients’ health, for instance research about the improved health of patients with type 2 diabetes, and another about an app enabling empowerment of elderly in a nursing home.\(^5\) An app that serve as technical medical equipment that entails a higher risk, i.e. that provides with basis data to base a diagnosis on, is mandatory to CE mark and is regulated under Directive 93/68/EEC. The CE mark imposes a responsibility for the manufacturer and that it is safe to use if the instruction manual is followed. The popularity and the high potential of apps will most probably result in many more empirical studies in within the nearest future.\(^6\)

The usage of smartphones is today more accepted and even welcomed in clinical environments. The recognition of the smartphones and their capacity to assist in providing freestanding software, apps, to patients, strengthens their position as a health tool.\(^7\) A patient-driven health care service is emerging to supplement and extend traditional health care delivery models and can be defined accordingly:

“Patient-driven health care can be characterized as having an increased level of information flow, transparency, customization, collaboration and patient choice and responsibility-taking, as well as quantitative, predictive and preventive aspects.”\(^8\)

The patient-driven health care seems to be driven by patients and allow them to get a sense of empowerment, to gain power and capacity over their situation by increase patients influence and responsibility-taking. It will probably contribute to better healthcare since it aims at being more customized and focuses on the individual patient, so called patient-centered healthcare. There is a great poten-

\(^4\) Dayer et al., p.172-181
\(^5\) Karolinska Institutet’s clinical research: Type 2 diabetes & Örebro University’s clinical research: App gives elderly empowerment
\(^6\) Council Directive 93/68/EEC Article 12 (1) and Article 15 (a) & The Swedish Association of Health Professionals on CE marking, p. 31-33
\(^7\) Medical Product Agency, p. 18-19 & Karolinska Institutet’s clinical research: Type 2 diabetes
\(^8\) Swan p. 512
tial for patient support systems to improve the health care system for chronically ill children and their families by making the patient feel better, enabling new ways for the professionals to learn new things about how it is to be a patient and the healthcare to be more effective. The shift to a more patient-focused and patient-influence healthcare is due to the view on patients’ role in the Western world has undergone a significant change over the years. We can see an ongoing movement towards the type of healthcare, which gives the patient a more active role in the relationship between patient and doctor.\(^9\)

Genia, a patient support system is an app for patients, foremost children, with the chronic disease Cystic Fibrosis and their family. It aims to enable children and their families, the healthcare and other professions related to the treatment, to share useful information. The app aids the child and family to record their observations and challenges of the everyday life, such as the child’s psychological health, the healthcare at home, physical exercise, spirometric measurement and antibiotic intake. Patient support system can be described as technical service, via app or website, that provides several tools to support patient in their daily life by. Patient support systems can create a bridge between patient and care and it can do so more effectively through the use of Internet. By using cloud computing a provider can process information about the child over the Internet. NIST, an agency of the U.S. Department of Commerce, has defined cloud computing as a model that has five essential characteristics: on-demand, broad network access, recourse pooling, rapid elasticity and measured service.\(^10\)

Patients who use patient support systems may at some point have to feed personal information into the service. The key words of the handling of personal information are: personal integrity (Swe., personlig integritet). The word integrity has evolved from the Latin word \textit{integritas}, meaning untouched, whole.\(^11\) Integrity is associated with worth and dignity, which is every person’s inalienable right and it is a right that cannot be waived, not even by the person him-

\(^9\) SOU 2013:2 p.76 & SNS: networks improve healthcare for patients with chronic diseases, p. 1-3
\(^10\) NIST p. 2-3
\(^11\) Encyclopaedia: Integrity
self. It also entails a right to decide what to do with information about oneself. The integrity could be violated or threatened in different ways. The right to keep some information to oneself is quite central in Section 1 PUL that states,

“The purpose of this Act is to protect people against the violation of their personal integrity by processing of personal data.”

Personal integrity is a central issue in patient support systems if information is collected or stored in their servers. Patient support systems and eHealth, a generic term for new service models within public healthcare that connects patient and provider through information technology, will most probably grow in the modern society and be a natural tool within the modern healthcare. Until then, it is vital and the responsibility of the provider of the patient support system to ensure that the child’s integrity is protected.

Genia has currently launched one version of the app for both children and parents/legal guardians to use. That means that both parents and children can access the platform for interaction and training diary called Genia Space, and participate and read the correspondence there. But not all children appreciate that parents are able to see what they write on the platform for interaction. The idea of the platform is to enable interaction and communication and the idea behind it is similar to Facebook and Twitter. As an interviewed child with Cystic Fibrosis said,

“It’s good that they [the parents] can see what I do and how I feel like in the tool “What’s up?” But I’d also like to be able to speak to other children and have little privacy in Genia Space. I don’t want them [the parents] to see everything.” - Leah, 11 years old.

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12 The Swedish National Council on Medical Ethics
13 The Data Inspection Board: Personal Data Act
14 Eysenbach
1.2 Purpose and research questions

With new technology comes great responsibility. A legal challenge with patient support systems is the child’s right to his or her own privacy and information. The integrity of a child who uses a patient support system, such as Genia, must be protected and there are several aspects of the integrity that is of concern. The aim of this thesis is therefore to elucidate and examine different questions concerning a child’s integrity in a patient support system.

The first question to be analysed is the legal criteria a provider of a patient support system fulfil to protect the integrity of a user. This question is important because of the personal data that is processed and it could be of very private and sensitive nature, i.e. concern the health status of a child. The personal data is most definitely a great concern of the child and the safeguarding of integrity. The integrity of children is of great concern from a legal aspect since they are a group that are unable to protect themselves and their integrity on their own, hence the importance that a provider of a system meet the criteria set by the legislator. It is also important to examine on what grounds a patient support system can fall outside the provision of the legislation that regulates process of individuals personal information. There may also be patient support systems that have a service where the user can send information to the healthcare. If such service is offered, when can the responsibility of personal information be shifted onto the healthcare?

With integrity comes the notion that one has the right to determine what information a person wants to share. Does a child have a right, and has it reached the level of maturity (Swe., mognadsgrad), to exclude parents from insight to and take part in a networking service, a platform for interaction? According to the Swedish Parental Code (FB), a child’s right to his other own integrity increases with age and maturity, but the legislator has not specified the age when the child upholds such right. The legislator has left it open to decide on when a child is mature enough, on an individual level.\(^\text{15}\) There is a possibility that a child in pre-teen years, age 9-14, does not want to share sensitive information

\(^{15}\) Prop. 1988/98:67 p. 36
with parents. The need for wanting to keep some things to themselves depends on the child’s maturity and other factors, such as family relations. A child younger than 15 years old may feel that it has reached a level of maturity and therefore does not want to not disclose all the information to the parents. Of course, not all children want to exclude parents or feel they have the need to have the sort of privacy this thesis is discussing, but there are children such as Leah, see quote above, who would like to have some privacy, especially when they are on the threshold on becoming teenagers. But the question remains, is it possible for a child to withhold information, for example on Genia Space, from parents? A discussion will be held on if a child can uphold such right and an analogy will be made to the relatively strict healthcare legislation about the child’s right to integrity. The thesis will also discuss what parents and provider, of patient support system, can contribute to in giving children privacy, on for instance Genia Space, a platform for interaction.

The research questions are:

- What legal criteria must a provider of a patient support system fulfil to protect the integrity of a user?

- When can Section 6 PUL be applicable in patient support systems

- When can the healthcare be responsible for the information shared by a child through a patient support system?

- Does a child have a right to exclude parents from a platform for interaction in a patient support system?

- What can parents and a provider of patient support system do to ensure that a child get the privacy on a platform for interaction?
# 1.3 Method and Material

The thesis examines the questions in the light of a patient support system called Genia that will provide the reader with a better understanding of how the legislation is applied to the services of a patient support system in reality. Even though there will be a general discussion about the legislation and the responsibilities of processed personal data, it will also discuss it from Genia’s point of view and the services that the service offers.

The method used in the thesis is in Swedish called rättsdogmatisk metod, which is based upon the traditional legal method, where the essential issues are identified and analysed in accordance with the hierarchy of legal sources (Swe., rättsskällarlän). The current Swedish law and regulations in this field will be clarified and analyzed following the hierarchy of legal sources. Case law (Swe., rättspraxis) on the area of child’s integrity with regards to patient support system is very little. However, there are a few decisions made by the Data Inspection Board, the authority appointed by the Government to perform supervision, on the usage of cloud computing and their inconsistency with Swedish legislation. Due to the lack of explicit case law, an analogy with the case law in the healthcare will be made that will show the challenges when deciding whose interest should be safeguarded in different situations, a child’s or parents’ interest. A comparison will be made with case law on the area of healthcare about to children’s right to integrity towards their parents.

Furthermore, the child’s right to integrity will be discussed on both an international and national level and it will lead to the discussion about whether or not a child can legally exclude parents from accessing Genia Space. This thesis will at the end of the thesis suggest ways for parents and provider to meet the child’s desire to exclude parents from Genia Space. It is important to distinguish between de lege lata (the legal position as it is) and de lege ferenda (the legal position as it ought to be). The suggestions are solely a result of my own thoughts and I am not by any means suggesting that this is how the legal

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16 Kleineman p. 21
17 Kleineman p. 36
position ought to be. Nevertheless, I find it very interesting to discuss this issue and the suggestions will be based on ideas of consent, terms and conditions, and supervision of the platform. The analysis will be continuously carried out throughout the thesis and not presented in a chapter at the end of the thesis. The analysis will therefore be intertwined in every chapter.

The material used in the thesis is mainly traditional legal sources, however other sources will also be presented. The material used for this thesis will include both international and national sources. Articles from the United Nation’s Convention on the Rights of the Child that are relevant to the thesis will be presented. The thesis will also mention a Directive of the European Parliament and of the Council and case law from the European Court of Justice that discusses the process of personal data, and The European Commission work regarding strategies for the development of eHealth services.

As mentioned earlier, the thesis will follow the hierarchy of legal sources and when it comes to material it will follow the doctrine of traditional legal sources that keeps an order of precedence for the traditional legal sources (Swe., standardkällor). There will initially be an introduction of two of the four Constitutional Acts (Swe., grundlagar), the Freedom of the Press Act (TF) and the Fundamental Law of Freedom of Expression (YGL). After that an analysis of current and relevant legislation (Swe., lagstiftning), which consists of parliamentary acts (Swe., lagar) and government regulations (Swe., förordningar), will be held. Other important materials are the legislative preparatory works (Swe., förarbeten), because of their high degree of authority in the Swedish legal system and also, official letters (Swe., skrivelser) will be part of the thesis. The preparatory work is a unique and distinctive Swedish source that provides details that is missing in the statutory legislation. The courts and advocates often turn to the preparatory work to find an answer to a question or an issue that cannot be found in the legislation, doctrine etc. The preparatory works that are relevant in this thesis are related to a child’s integrity and the handling of personal data and helps us to understand the Government’s view on what the law is and what it ought to be.
The list of case law on the area of children’s integrity in patient support systems or apps in general, is very short and is almost non-existent. The few decisions that exists will be highlighted are made by the Data Inspection Board. It will therefore be difficult to find case law that says much about the questions of this thesis, which is why an analogy with the healthcare will be made. The purpose of the analogy is to identify and see the discussion regarding the child’s interest and integrity versus the parents’ right to insight to the child’s private life.

The last traditional legal source that will be used is legal scholarship (Swe., doktrin) that is an important source in Sweden hence, used by the courts. There will also be a large amount of digital sources because of the lack of clarified legislation (i.e. the child’s right to integrity increases with age, but when?), and case law on the subject.

1.4 Demarcation

The main focus of this paper will be the integrity of the child, but not all aspects can be covered in this thesis, and that is not the intention either. The aspects that will be the subject of the thesis will mostly be seen at from a child’s point of view but also the provider’s and parents’ when looking at parent’s consent and the safeguard measures a provider can contribute to.

Genia is collaborating with the healthcare and has developed a function where a child can send a pre-visit form, a PDF, with health-related information that is sent from the user. The pre-visit form can be sent to the clinic before the monthly or annual check-up and is used to make both patient and the professionals to be better prepared for the meeting at the clinic. It will briefly discuss the role of the healthcare, which is an important stakeholder, as a controller of personal data, and its legal responsibility in the scenario where a child sends a pre-visit form through Genia. It is interesting to examine the healthcare’s role as a controller of data and how the responsibility can be shared or even shift from a provider to the healthcare in different scenarios. However, the thesis will not go in-depth into this because the thesis does not have the healthcare’s
angle of vision. The healthcare will also be mentioned when the analogy is made between case law of healthcare and patient support systems run by private provider.

Furthermore, the other focus will be on the app’s the platform, Genia Space, and the possibility for children to have privacy there by excluding the parents from participating. The parents’ role and impact will be discussed when it comes to how the integrity of a child corresponds to their parental duty and further how the parents can contribute to the strengthening of the child’s integrity when consenting to being excluded hence giving the child the privacy on Genia Space. The provider’s point of view will also be discussed when writing policies and terms and conditions that contribute to the safeguard of the child’s integrity and the parents’ consent. Some relevant ethical perspectives are going to be discussed but to a limited extent. The ethical discussion obviously gives perspective to the question about the child’s right to privacy but it is not an exhausted explanation because the ethical issues are based on values and it is a matter of subjectivity.
2 Genia – a patient support system

2.1 eHealth

According to WHO, eHealth refers to the transfer of health resources and healthcare by electronic means.\textsuperscript{18} Both patient-driven healthcare and patient support systems derive from the idea to effectively transfer health resources. The meaning of the letter e, does not only stand for electronic, but it also entails different meanings, such as efficiency and enhanced quality, empowerment, encouragement and education.\textsuperscript{19} Not only could eHealth improve the use health recourses but also be used as a new medium for information dissemination and also for more effective way to interact and collaborate with other institutions, health professionals, health providers and the public.\textsuperscript{20} Not only will eHealth increase in efficiency due to reduced costs, but at the same time also by improving quality.\textsuperscript{21}

There is an international acknowledgement of eHealth and its opportunities to quality improvement within the healthcare and increase access.\textsuperscript{22} It has been recognised, not only in Sweden but also by the EU. The European Commission first eHealth Action Plan was adopted in 2004, and have since then has set up strategies for the development of eHealth services, The Directive on the Application of Patients' Rights in Cross Border Healthcare and its Article 14 establishing the eHealth Network, adopted in 2011, marked a further step towards formal cooperation on eHealth. The aim is to maximise social and economic benefits through interoperability and to implement eHealth systems. The response from the Member States has been dynamic and it shows that there is a high level of commitment to the eHealth policy agenda, i.e. through their par-

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\textsuperscript{18} WHO & SOU 2006:82 p. 137
\textsuperscript{19} Eysenbach
\textsuperscript{20} WHO
\textsuperscript{21} Eysenbach
\textsuperscript{22} Ibid.
\end{flushleft}
ticipation in major large-scale pilot projects.\textsuperscript{23} One of them being epSOS5.\textsuperscript{24} Also, the WHO has adopted a resolution about eHealth where they urge member states to undertake long-term strategic plans for developing and implementing eHealth services in various of areas of the health sector.\textsuperscript{25}

In Sweden, there is the Swedish National Strategy for eHealth that aims to adapt new ways of service deliveries within the Health and Social Care sector such as Mina Vårdkontakter (My health care contacts).\textsuperscript{26} It seems that patient support systems are welcomed and are seen as a new way to compliment the healthcare by making it more sufficient. By allowing patients to contribute and collaborate more with healthcare professionals we seem to move towards a more patient-centered healthcare. Genia, amongst other patient support systems are therefore very interesting for not only patients and the healthcare professionals that are on a micro-level but also on a macro-level, for the country and the EU.

\section{2.2 Cystic Fibrosis}

Cystic Fibrosis is a rare and life-shortening genetic disease caused by a gene mutation. Thick viscous secretions characterize the disease, which leads to a failure in the respiratory system to transport all of the mucus out of the lungs. The thick mucus that is left in the lungs cause a blockage of airways and result in coughs, shortness of breathe and frequent lung infections that are treated with antibiotics and other medications. There are also other symptoms affecting different parts of the body.\textsuperscript{27} There are approximately 670 patients with Cystic Fibrosis in Sweden, which equals to 7/100 000 citizens, and the number of children born with the disease is 20.\textsuperscript{28} A person with Cystic Fibrosis cannot

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\textsuperscript{23} European Commission p. 3  \\
\textsuperscript{24} EpSOS is a pilot project that came to an end in June 2014. It aimed to offer seamless healthcare to European citizens. The projects key goals were to improve the quality and safety of healthcare for citizens when travelling to another European country and focused on developing a practical eHealth framework and ICT infrastructure that enables secure access to patient health information among different European healthcare systems.  
\textsuperscript{25} WHA58.28, Section 1, p.121  \\
\textsuperscript{26} Ejenåns p. 7, 9-10, Skr. 2005/06:139 p. 6-7 and My health care contacts  \\
\textsuperscript{27} Vårdguiden & The National Board of Health and Welfare: Cystic Fibrosis  \\
\textsuperscript{28} The National Board of Health and Welfare: Cystic Fibrosis
\end{flushleft}
be cured; however there are several treatment methods that enable an individual with Cystic Fibrosis to live a fuller life and also to live longer than expected. The treatment puts a high demand on both the patient and his or her family. Self-management consists of respiratory and physical exercise, often perceived as burdensome, and can take up to two hours a day.29

2.2.1 Patient support system decrease risk of cross-infection

For children with Cystic Fibrosis, cross-infection can be harmful and is therefore a threat to their health. Compared to other people, the individuals with Cystic Fibrosis are vulnerable to different bacteria or bugs that grow in their lungs. These bugs can easily be transmitted onto other people with Cystic Fibrosis, so called cross-infection. Due to the infection risk, they are advised to not to meet in person.30 For these children it means that they rarely can meet others with the same disease and same struggles and that is why patient support systems are great tools for them to interact and overcome the physical obstacles. Patient support system provides them with a platform for interaction from which they can share experiences and communicate with other children with Cystic Fibrosis.

2.3 Genia

The care for a patient with chronic illness has for the last fifty years changed and the way of interaction has gone from fairly clear and simple between patients and professionals, to often quite complicated systems of care.31 There are approximately 670 patients who suffer from the chronic disease in Sweden.32 The app Genia is a patient support system, initiated by the Swedish company Chimes. The idea behind Genia is to enable patients and families living with Cystic Fibrosis, the healthcare professionals (Cystic Fibrosis-team) and other healthcare professions related to the treatment, to share useful health-related

29 Vårdguiden & The National Board of Health and Welfare: Cystic Fibrosis
30 Badlan p. 264-270
31 Batalden et al., p. 549-551
32 Kvalitetsregister
information. Its purpose is to make the everyday life easier for patients, especially children who are bearers of this disease, and their families. The focus group of the app is children with Cystic Fibrosis and to provide them with an app that assists them in their management of their disease.

Genia consists of four functions: What’s up (a function that allows children to type in their mood and thoughts about their health), Medication (notes on medication), Notes and Genia Space. The app’s different functions enables children and family to record their observations and challenges of the everyday life, such as the children’s psychological health, the healthcare at home, physical exercise, spirometric measurement and antibiotic intake. One of the main functions of Genia is to facilitate collection and storage of personal data and observations to the healthcare professionals, prior to the appointed clinic visit, for instance with the help of pre-visit forms. The goal is to improve the monthly meetings at the Cystic Fibrosis clinic by helping healthcare professionals to be more informed about the patient’s health experience and to understand their situation. The provider of Genia has based the app on cloud computing. For a child to register for an account and for Genia to collect children’s personal information, Genia has to acquire parental consent because there is a thumb rule that a child under 15 is not capable of understanding the meaning of consent.33

2.4 Cloud computing

There are a lot of definitions on cloud computing. A search for it on the Internet will result in approximately 11 million results. NIST’s definition of cloud computing can be summarised as a model when needed (on-demand) to enable network access to a shared pool of configurable computing resources, for instance, networks, servers, storage, applications, and services. The recourses can then quickly be accessible and released with minimal management effort or service provider interaction.34

33 SOU 1997: 39 p. 279
34 Edvardsson et al., p. 21-22 & NIST p. 2-3
The provider of Genia has divided the service into two types of clouds, *private cloud* and *community cloud*. Some of the user’s information is collected and stored, and some is not. The infrastructure of the private cloud is provisioned for exclusive use and that use is reserved for registered user with an account. The private cloud is used as a personal account. It is organised, managed, owned and operated by Genia but it exist off premises meaning that Genia does not access or use information other than to do statistics, which users consent to. Other than that, Genia does not process any information in the personal account.35 The personal account is a private sphere on the Internet where the user can add notes and health-related information and is not shared with others unless the user approves of it. The private cloud can be compared to the idea of personal accounts on Dropbox or Evernote. The idea behind the personal account in patient support systems is interesting because the idea was presented in a pilot study called *Din journal på nätet* (Eng., Your Medical Records on the Net),36 see chapter EHR-PHR.

The community cloud, on the other hand, is based on an infrastructure that is provisioned for exclusive use by a specific community. Children and parents share the same community cloud and use it exclusively, none other than users and Genia can enter it. The community cloud is open to users and allows Genia to access the information within the cloud. Genia Space is an example of a community cloud, with a specific community, that is all individuals who have registered for an account. The users of Genia Space share for instance the same security requirements and policy.37 Its content is shared amongst others and is not like the information on the privacy cloud, where the only one who can see the content and store information is the user. Since the information in a community cloud is shared with others and also processed, i.e. when a child posts something or sends a message, Genia or more specifically the person responsible is for the handling of the private information. The information in Genia Space and the consented information that the provider has falls under the pro-

35 See Chapter: Data storage
36 *Din journal på nätet*: Final report
37 Edvardsson *et al.*, p. 28-29 & NIST p. 2-3
vision of the person responsible for management of personal information on Genia.

2.5 Genia Space

Genia Space is the platform for interaction as well as a training diary and aims to support motivation to daily treatment. It is a platform under development and is inspired by social networks such as Facebook and Twitter, where communication and experience exchange are watchwords for meaningful meetings. The idea is to provide a platform for children where they can share thoughts, put up posts of training or daily life events and, share and communicate with others openly on a type of news feed, or through private messages. The communication on Genia is encrypted. In order for a person to access the app and its content, one would have to register an account and identify oneself with a username and password.

The provider has chosen to let some functions to be private, where the user is the only who can access the information such as the service, Medication. Other users such as parents may also access it, and there is a process for that but it will not be discussed in the thesis. There are also some functions where the information is shared in the open and in a community, such as Genia Space. On Genia Space, the users can write to each other, and in the nearest future perhaps post update status on news feed, and share things on a personal profile. Genia Space is a place for interaction and exchange. The provider has access to the information on Genia Space and is using and handling the information in different ways. Information is being handled for instance when a user writes to another user because the information that a user types into the platform is processed and then sent to the other user. Nonetheless, all process of data must be consented by users.

2.6 Data storage

A provider who has divided the app into a community cloud and a private cloud, where some information is for instance stored in servers and some in-
formation is not. The responsibility for the information is not always the providers or the person responsible for the app’s process of information.38 There is some personal information that will only be accessible to the user. The security of the information on a private cloud is dependent upon users and their private use of the security features on their smartphone. The health-related information, notes, medication etc. that a user feeds into the app can be classified as sensitive information and such information is stored in a personal account. The pre-visit form that includes information about the health can be sent from the private cloud. The pre-visit form is therefore not store the Genia. The provider only provides the user with the service to export the file and it is done the users personal account to the healthcare.

There is however information that is not only accessible by the user. According to Genia’s privacy policy, Genia is saving user’s username, email address and contact preferences to create and support the users Genia service account and to communicate with the user. They keep statistics on the user’s habits and what functions they use, for instance how many users use the tool Medication and how often. Of course, the provider must have the users consent to keep statistics on their habits. The information that the patient support system collects about habits cannot be traced to a specific user because the only thing that is shown is numbers and statistics. A user, whose information Genia collects to do statistics, is anonymous and can therefore not be identified. It is interesting to see how a patient support system can be structured and that there is a possibility to arrange the app so that a provider does not access information and hence, not be responsible for it being processed according to legislation.

38 See chapter 4, Legislation
3 Patient support system in collaboration with healthcare

3.1 EHR-PHR

The Swedish Government acknowledged the positive and potential outcomes from eHealth and initiated the National IT-strategy for healthcare (Swe., Nationella IT-strategin för vård och omsorg) in 2005 and 2006, presented in the Government Communication 2005/06:139. The initiative engaged all the Swedish City Councils (Swe., landsting) and they decided to establish a common action plan to adopt and implement the IT-strategy.

One of the goals of the IT-strategy is to provide patients with a platform in which patients could get accessibility and overview of his/her records, prescriptions and previous visits to the healthcare. This platform would also enable the patient to make notes in order to share them with the health professionals and to be able to trace others that took part of such information. In 2010, the IT-strategy was renamed and is now called National eHealth – the strategy for available and secure information within Health and Social Care (Swe., Nationell eHälsa - för tillgänglig och säker information inom vård och omsorg).

During 2011, Inera AB carried out the pilot study Din journal på nätet on behalf of CeHis, one many projects of the National eHealth. The aim for the pilot study was to elucidate opportunities for the health records to be made available for patients over the Internet and also to point out what ethical, medical and judicial consequences there are if health records where to be made available in such way. The pilot study Din journal på nätet showed that both healthcare professionals and patients express a need to communicate and interact electron-
ically within the healthcare. Even though the pilot study concentrates on investigating the need of a health account, managed by the healthcare, there are some interesting observations that can be discussed in the light of private providers of patient support systems.

The Patient Data Act (PDL) permits health professionals, mainly health providers, to provide a service where a patient can seek and read information via an account. The tool is often called “hitta och titta” (Eng., “find and see”) which in international terms is referred to as EHR – Electronic Health Record. The term EHR is often used for a system from which a patient can look at, but sometimes it refers solely to an electronic record system. While an EHR system enables patients to seek and find information related to their health, there is no available system within the healthcare in which the patient can attain an active part of it by becoming a contributor to the health record. This was also affirmed in the pilot study where a conclusion was made that patients find that an EHR system is not sufficient in meeting the patients’ needs. The EHR system is also not equipped to handle the challenges of the future healthcare. The patients are primarily asking for increased accessibility and better communication and more interaction, which also is beneficial for the process within the healthcare. The results of the study show that there is a demand by patients for a platform or a system that allows patients to contribute to their health and this ought to apply for children as well because they are very much involved in their health. The documented reaction and need for such platform is a visible plea of the patient to improve the information the healthcare uses as to support their decision-making.

The pilot project came up with a solution to the problem, called PHR – Personal Health Record that provides patients with a personal account. The PHR system allows the patients to add notes and medical on their personal account, through the Internet, and to contribute to their health improvement by having a more active role. It provides a more flexible platform, enabling patients to be more

43 Din journal på nätet: Delrapport 2, p. 27
44 Ibid p. 26-27
45 Din journal på nätet: Final report, p. 8
active and included in their healthcare that before. The PHR system enhances the patients’ elaboration with the healthcare, for instance by allowing the patients to participate in collecting and documenting useful information concerning their health.\textsuperscript{46} Genia is built and inspired by the PER system. The app enables users to add personal notes to their health-records, via pre-visit forms, or in other way contribute to their health documentation and quality of health care.

Since Genia is a limited company who uses such system PHR, a cloud service for its processing of personal data, the company is controller of the personal data. It is therefore the legal entity i.e. the limited company that will be held responsible if the company does not process the personal data in compliance with the Swedish regulations.\textsuperscript{47}

\begin{figure}[h]
\centering
\includegraphics[width=\textwidth]{diagram.png}
\caption{Diagram of data flow between different accounts.}
\end{figure}

Picture: Din journal på nätet: Remissunderlag, p. 12.

The care provider sends health-related information from Fack 1 to Fack 2, from which the information is sent to the receiver in Fack 4. The receiver is the patient and the information is sent to the patient’s personal account and cannot be

\textsuperscript{46} Din journal på nätet: Delrapport 2, p. 7
\textsuperscript{47} See chapter 4, Legislation
accessed by healthcare. If a patient wants to send health-related information to the health provider and the patient’s own medical records (Fack 4), he or she does so by sending it through Fack 3, which is an export surface. EHR and PHR have both two separated accounts. While the EHR is regulated by PDL, the PHR is not and is therefore subject to private providers who regulate the service through contract law.

The model of EHR-PHR system can be a tool for providers of patient support systems who want to collaborate with the healthcare. The information in a patient’s account (Fack 4) is neither shared nor accessible for the healthcare. Since it is not processed or accessible to the health provider it cannot be a responsibility for such personal information (data). Genia has adopted the idea of a PHR system by providing users with a personal account that has the same concept as Fack 4, where Genia has no access to the users’ information. The personal account is detached from Genia and the community cloud, and is solely managed by the user/patient. Patient support systems that want to collaborate with the healthcare and use the model EHR-PHR can provide with an export and import surface from which health provider and patient can send information back and forth.

3.2 Connection to the National eHealth Service System

The patient support system is connected to the healthcare system via the National eHealth infrastructure. The flow of information between care provider and user is today a pre-visit form with health-related information that is sent from the user, similar to the EHR-PHR model. The pre-visit form and all the information on it is on the user’s private cloud, also referred to personal account. It is not collected or stored by Genia. The pre-visit form must be structured in a certain way in order for it to be integrated with the National eHealth service platform. Before information is sent to the healthcare system it has to be authorised by patient or parents/legal guardians. It is done through a service that fulfils the demands on encryption, authentication and validation. Users must identify themselves with an electronic signature, such as Bank ID, to send
the pre-visit form to the healthcare. In Sweden, the majority of the Swedish banks use BankID, the leading electronic identification based on Public Key Infrastructure (PKI). It is an advanced signature and according to Swedish law and within the European Union, a signature with BankID is legally binding. As BankID is often used for digital identification as well as signing contracts and documents, it would be a proper way to identify oneself as a parent digitally and accordingly legitimise the consent.48

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48 BankID
4 An analysis of current legislation

Providers of patient support systems may use the personal information a user is feeding into the system in order to assist patients, which often entails the handling of sensitive information about their health. The question is what measures the legislator wants a provider to take to safeguard the personal information, when the legislation is applicable and who is responsible for it. Also, it is vital to research on what legal position a child, including towards parents.

4.1 The provisions of PUL

When a person wants to register for an account in a patient support system, he or she has to register personal information, such as name, surname, address etc. The registered personal information is what PUL describes as personal data. The handling of a person’s personal data is regulated both on European level and national level. The implementation of PUL was introduced as a safeguard measure to protect individuals against the violation of their personal integrity when personal data is being processed (Section 1), and on the free movement of such data. However, there are a few exceptions and according to Section 7 PUL, the Act is not applicable if there is a collision with the constitutional protection for freedom of expression, contained in TF and YGL.\textsuperscript{49} PUL is based on Directive 95/46 of the European Parliament and of the Council of 24 October 1995.\textsuperscript{50} The Swedish courts and authorities are obliged, according to general principles of European Union law, to apply the law in accordance with the Directive and the interpretation of the European Court of Justice.

The process of personal data occurs when information about a user is used or managed. The term processed data implies collection, recording, organisation, storage, adaptation or alteration, retrieval, gathering, use, disclosure by transmission, dissemination or otherwise making information available, alignment or combination, blocking, erasure or destruction. The term process is applied to

\textsuperscript{49} SOU 2007:22 p. 433 & SOU 2004:114 p. 27
\textsuperscript{50} The Data Inspection Board: Personal Data Act
any operation/set of operations that are conducted with regards to personal data, regardless if it occurs by automatic means or not, Section 3 PUL. The description of personal data in PUL includes all kind of information that directly or indirectly that can be referred to a person who is alive. A provider often uses the information that is fed into the app by the registered user, and if that personal data is saved, collected or is stored; it is a process that fits PUL’s description. According to the Article 2(d) of Directive 95/46 and Section 3 PUL, a controller is the one who, alone or together with others, decides the purpose and means of processing personal data.\textsuperscript{51} Although the Article 2(d) of Directive 95/46 and SOU 1997:39 state that a controller could be a natural or legal person, the Data Inspection Board proclaims that the controller of the personal data is often a legal entity i.e. limited company or an administrative authority.\textsuperscript{52}

There are a numbers of fundamental rules throughout PUL that a controller of must follow. The rules in Section 9 a-i is set out to guide the controller. For instance, personal data is processed only if it is lawful, (9a), personal data is only collected for specific, explicitly stated and justified purposes, (9c), no more personal data is processed than is necessary having regard to the purposes of the processing (9f). A controller is for instance permitted to turn personal data into statistics like the statistics used in Genia to monitor the users habits. In a Swedish Government Official Report\textsuperscript{53} it was concluded that information processed into figures and statistics is permitted if consent is given for the processed data and it does not mean that there is further intrusion into the personal integrity. Statistics could help a provider or controller of personal data to see how often the different functions of the app is used etc. and based on that, improve the app.

The Act only applies to those controllers of personal data who are established in Sweden and when the controller of personal data is established in a third country but uses equipment located in Sweden for the processing of personal

\textsuperscript{51} Directive 95/46 & SOU 1997:39 p. 336  
\textsuperscript{52} SOU 1997:39 p. 332, Directive 95/46 & The Data Inspection Board: The control of personal data  
\textsuperscript{53} SOU 1997:39 p. 310
data, Section 4 PUL.\textsuperscript{54} This is quite essential when discussing whether or not a provider of a patient support system is obliged to follow Swedish regulations. The equipment probably is physical things and not acquired information from a database abroad. That means that support systems such as Genia that have their servers in Sweden are covered by the Act.\textsuperscript{55} There could be a scenario where a provider is based in a third country, for instance Bahamas, and that runs the app from there but have some sort of equipment in Sweden. However, a provider who is running the app from a third country and does not have any equipment in Sweden is also free and is not responsible for the processed personal data that is collected from Sweden. There are for example a lot of health-related apps, and other, that are not under the prevision of PUL because they are run from a third country even though people in Sweden download it and use it.

For a provider of a patient support system, whose audience includes or address children, the central concern is the process of the children’s personal data and information. The articles in PUL are mostly based on consent and adequate information to the registered individual.\textsuperscript{56} It is a fundamental right to be aware and approve of such actions that affect the registered person. For a provider such as Genia, it is vital to obtain the consent of users to use their personal data or fulfil the criteria in set out in Section 10 PUL. Consent is according to the Section 3 PUL, every kind of voluntary, specific and unambiguous expressio of will by which the registered person, after having received information, accepts processing of personal data concerning him or her.\textsuperscript{57} Consent can only be valid if given by someone who is capable to understand the meaning and the consequences. A child under the age of 18 is eligible to give consent to processing of some personal data if he or she understands the meaning of such consent but it must also be consented by the parents.\textsuperscript{58} Depending on the maturity, age and the purpose of the processing of personal data, the parents’ consent may not be needed. The thumb rule is that a child over 15 is capable of

\textsuperscript{54} The Data Inspection Board: The Personal Data Act
\textsuperscript{55} Edvardsson et al., p. 101
\textsuperscript{57} The Data Inspection Board: The Personal Data Act
\textsuperscript{58} The Data Inspection Board: Consent
understanding the meaning and consequences of a given consent. The regulation is stricter when it comes to a child giving consent to historical, statistical or scientific purposes.\textsuperscript{59}

A failure or negligence to obtain consent, or meet the other criteria in Section 10, could result in the controller of personal data paying redress and compensation to the individual, Section 48 PUL. All the processed personal data through a patient support system must be handled according to the agreement and the user’s consent. It is not permitted to process information other than what it is agreed on and the legislator is very clear about it by imposing different legal actions against such act. The Act also mentions other forbidden actions that an individual takes that can lead him or her to be sentenced to fines or imprisonment, Section 49 PUL.\textsuperscript{60} An individual who undertakes illegal actions don’t necessarily have to be the controller of personal data, it could be a personal data representative, which according to Section 3 PUL, a natural person, appointed by the controller of personal data, who shall independently assure that the personal data is processed in a correct and lawful manner. The fact that the Act refers to an individual and not a specific person, such as a controller, is vital because that means that a provider of patient support systems cannot delegate the tasks of process to someone else, a third party, and get away with breaching the law. According to Section 3 PUL, a third party is a person other than the registered person, the controller of personal data, the personal data representative, the personal data assistant and such persons who under the direct responsibility of the controller of personal data or the personal data assistant is authorised to process personal data. Sanctions may be imposed on some actions that an individual consciously undertakes knowing that the process is illicit, as well as someone who is unaware of it being illicit. The Government decided that it was legitimate to impose sanctions, fines and imprisonment, on some actions that were more serious, such as transferring personal data to a third country and illicit process of sensitive information.\textsuperscript{61}

\textsuperscript{59} SOU 1997: 39 p. 279
\textsuperscript{60} The Data Inspection Board: Consent
\textsuperscript{61} SOU 2004:6 p. 198
In recent years, the Data Inspection Board has been scrutinising the usage of cloud computing and found that many costumers and providers of this type of IT-services, including counties, have failed to meet the legal requirements in PUL. In the last couple of years the Board has made several decisions against counties and a company for not arranging adequate safeguard measures to secure the user’s integrity. In December 2014, the Board made decisions against two Health apps, VaccBook and MinHälsobok (Eng., My Health Book), criticised their handling of personal integrity and the processing of personal data. The Board’s expressed concern is not unwarranted, since controllers of personal data deal with extra sensitive information and dealing with vulnerable client’s, both applicable on Genia. In the two decisions, it was stressed that the user must be provided with information about the identity of the controller of personal data, Section 25a PUL. It is very important for a user to know the person responsible for his or her information, hence The Board’s criticism on the lack of available information. The Board also criticised VaccBook for not having routines for erasing of personal data, Section 9i PUL, when the app was deleted. The Board referred to The Article 29 Working Party’s opinion on apps on smart devices, stating that app developers should pre-define a time period of inactivity, after which the account will be treated as expired. It is also important that the user is aware of the timescale. The specific rules regulate different, and yet important questions regarding the process of personal data and even the handling of personal data after a user deletes his or her account. So far, it seems as if the legislation is able to cover the new challenges of patient support systems, apps etc.

The legislator has covered different subjects and specific matters that must be addressed to secure a persons information from being exploit and misused.

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62 The Data Inspection Board’s decisions against, Salems kommun (Salem County), Enköpings kommun (Enköping County), Sollentuna kommun (Sollentuna County) and företaget Brevo (the company Brevo)
63 VaccBook Dnr 1416-2013 & MinHälsobok Dnr 2059-2013
64 Article 29 Data Protection Working Party, p. 25
There is also sensitive information that a provider might deal with. It is noticeable that the legislation is stricter towards process of this type of information.

### 4.1.1 Sensitive information

When children or other group of patients with disease feed information into a patient support system, it could be sensitive information such as notes about medication, health and diagnosis. For a provider that collects information that is sensitive, it is vital to observe the legislation concerning such delicate matters. Section 13 PUL states that it is prohibited to process such personal data as concerns health or sex life. Nonetheless, several exemptions to the rule can be found in Section 14-20 PUL. Section 15 PUL states,

“Sensitive personal data may be processed if the registered person has given his/her explicit consent to processing…”

The legislation forbids information regarding health to be processed and used. However, the user’s consent can enable such process and can be required in order to create an account. The information about the consent must be shared with the individual before agreeing to the terms and conditions. The Data Inspection Board emphasizes the importance of information being clear and comprehensible. The information has to include contact information of the controller of the data, the purpose of the process of personal data and other details, such as, what type of data will be processed, to what companies or organisations may their personal data be handed out to, that the user has a right to demand an index or register to control what personal information has been registered. However, the user has the right to withdrawn his or her consent at any time, Section 12 PUL.

There is an exception to the provision of PUL, a loophole. A provider may be excluded from the provision of PUL as long as personal data is processed is of private nature, Section 6 PUL. If not, the provider is most likely to be a subject

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66 The Data Inspection Board: The Personal Data Act  
67 The Data Inspection Board: Information to the registered  
to PUL and further, has a notification duty according to Section 36 PUL. The controller of personal data shall provide a written notification to the supervisory authority, the Data Inspection Board, before the process is conducted. The provider is according to PUL is responsible for the process of personal data being in compliance with PUL and other Swedish regulations.

These issues are important to address for a provider that collects sensitive information. Since patient support systems aims at assisting patients in their daily struggle with disease-related issues, a provider ought to consider what type of information that is to be collected and processed. A provider could instead do like Genia, manage the app so that the sensitive information is fed into a private cloud where the user is the only one accessing it and the process purely personal.

4.1.2 Section 6 PUL - Operation of private nature

The PHR system is based on a system supplied by a provider that is not a caregiver but a private supplier, usually a company. According to the final report of the pilot study Din journal på nätet, the handling of the account holder’s personal information, in a PHR system, is done within an operation of a private nature. The operation of private nature is an exception in Section 6 in PUL, preventing the Acts applicability, stating,

“This Act does not apply to such processing of personal data that a natural person performs in the course of activities of a purely private nature.”

The Article has the same meaning as the Directive’s Article 3(2) that the Directive shall not apply the processing of personal data, “by a natural person in the course of a purely personal or household activity”. Many comments have been made on Section 6 PUL, illustrating the aim and essence of the rule. Examples of activities of private nature are electronic diary and registration of family and relatives, also private correspondence via e-mail is considered to be

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69 The Data Inspection Board: The Personal Data Act
70 Din journal på nätet: Final report, p. 9
71 The Data Inspection Board: The Personal Data Act
72 Directive 95/46/EC, Chapter I General Provisions, Article 3(2)
an exception. The European Court of Justice has ruled on the matter of the
definition of processing of personal data and further that was seen as an exception
to the Directive. In the case C-101/01-Lindqvist, the European Court of Justice stated that the exception only applies to activities carried out in the
course of private or family life of individuals and not to processing of personal
data that consist in publication on the Internet, enabling indefinite number of
people to access those data. The process of personal data, that a person process or keep of private nature, is therefore excluded from the implementation
of the PUL.

A system such as PHR could be excluded from the implementation of PUL
since it is not applicable on an individual who handles the personal inform-
information, where the processing personal data is of private nature. This is correct
as long as the provider of such a system does not collect personal data. Recently, the Data Inspection Board decided that Gravidappen, a pregnancy app, did
not fall under PUL since they found that the personal data is stored in their
personal account and the company does not have access to the information.

When the user erases the account, all personal data stored in the app is automa-
tically erased. The Board compared it to an electronic diary, notes solely for
private use and decided that the process of personal data was of private nature,
Section 6 PUL. Genia has written in their privacy policy that certain inform-
information about the user that will be collected for different purposes. The control-
l of personal data is therefore responsible for the information that is pro-
cessed, but not for the users process of his or her own personal information.
The users information such as notes on medication, documentations etc. is pro-
cessed in their personal account. The controller of personal data has no access
to a user’s personal data making the user the only one who is able to access his
or her personal data, with exception to the collection for statistics that is based
on consent. This way, all the personal data is stored in a private account, as
described in the pilot study and seen in the Data Inspection Board’s decision
about Gravidappen, is seen as a digital diary, making it a process of personal

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73 Karnov: a comment on Section 6 PUL
74 Case C-101/01, Section 47
75 Din journal på nätet: Final report, p. 18, 23
76 Gravidappen Dnr 1451-2013, p. 2
data of private nature Section 6 PUL. A provider who provides personal accounts to users and don’t process the information is no of no legal concern to a provider since that information is not within the controller of patient data’s scope of responsibility.

4.2 Shared personal data with the healthcare

PDL primarily regulates the processing of personal data within the health and medical services, and applies to all care providers. For instance, it regulates internal secrecy and electronic access within a care provider’s operation, the disclosure of documents and data through direct access or by other electronic means, national and regional quality register and addresses the obligation for the carers to keep patient records. The regulation is a part of an ongoing process to enable, through the aid of IT, better communication between the stakeholders within the health and medical care services but also to improve carers’ patient orientation.77

Once the care provider has handed over information to the patient, often in paper, the PDL no longer regulates it. The information is considered to be the patient’s property and the care provider have no longer control over how the patient uses that information, whether or not it is shared with others. This ought to apply for electronic information as well. The legislation does not regulate the type of service where patients can add notes.78 A private provider, not a care provider, provides Genia and that is why it is excluded from the provision of PDL.79 Genia’s account has an export interface to which a pre-visit form can be sent by the user and received by the care provider. The pre-visit form contains specified and structured information that can be saved as an entry in the patient’s medical records.80 The question is who is responsible for the processed personal data when it is sent to the healthcare, the provider or both, and when this personal data is a legal concern of the care provider. Even though this will not be discussed in depth, it is interesting to see the information ex-

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77 SOU 2006:82 p. 35-36
78 Din journal på nätet: Final report, p. 9
79 Ibid. p. 26
80 Ibid. p. 9
change and how it affects the responsibility of the controller. It is most probable that the care provider will be responsible for the patient’s personal data leading to such information being a subject put under the scope of PDL, Section 3. At some point the caregiver will process the pre-visit form. Depending on if the provider of a patient support system stores personal data, the provider could be responsible for it after the user sends it. In Genia’s case, the pre-visit form is set up in the personal account and is not stored by Genia and hence, not a controller of it.

The care provider would probably have to undertake certain safeguard measures before receiving the pre-visit form, for instance a security service that fulfils demands of encryption and validation of the patient by electronic identification, such as BankID.\textsuperscript{81} It is likely that a private provider might offer such security measures. The same demand for security service would apply, according to the new PDL, if a care provider hands out information to the patient over the Internet, i.e. to their Genia account.

The healthcare will most probably offer more services over the Internet, such as patient support systems or other services provided by the healthcare itself. Patients’ information that is sent to and from the health care is very sensitive and therefore crucial to structure the process in such way that it will not violate patients’ integrity.

4.3 The Parental Code

According to Chapter 3, Section 1 FB, a child has a right to be maintained and protected by its parents. Both doctrine and preparatory work stress that it entails to get ones physical, i.e. right to a adequate livelihood, and psychological needs met such as right to safety, stability and, having someone to depend upon and trust.\textsuperscript{82}

The ambition for this thesis is to discuss the children’s right to their integrity, not only towards a provider and third party, but also towards parents. There is

\textsuperscript{81} The Patient Data Act and personal integrity
\textsuperscript{82} Schiratzki (2013) p. 59
not a specific regulation in FB regarding the children’s usage of patient support systems. However, since Genia is dealing with health issues and handles sensitive information, it is of great concern to the parents who according to Chapter 6, Section 1 FB, have a parental duty to be the child’s care givers. The parental duty entails raising and educating a child into adulthood and foremost, providing the child with nursing care throughout their childhood. A child’s usage of the platform for interaction on Genia is arguably a matter of importance for parents, and thus, the discussion regarding the parent’s approval is central. A child who is younger than 15 years will probably have to get their parents consent to such service. As mentioned earlier, the Data Inspection Board has stated that a child is mature enough to give consent to the processing of his or her personal data at the age of 15.\textsuperscript{83}

Even though the parents, as care givers, have great impact on a child and are responsible for their care, the legislation has also acknowledged the child’s opinion and will. It stated in the second sentence of Section 11 of Chapter 6 FB, that a child’s right to integrity increases with age and maturity. This means that a child has a right to be heard in matters that concern them given that they have developed a sense of integrity. According to comments made on The second sentence of Section 11 of Chapter 6 FB, the Act does not clearly state at what age a child has reached such a maturity and to what extent a child’s opinion and will ought to weigh in, in personal matters. The question is when a child have a right to exclude parents from taking part of sensitive information on Genia and whether or not a child between the age of 9 – 14 has reached such age and maturity as implied by the Act.

4.4 Children’s ability to attain privacy through contract law

There are numbers of legal situations where the child’s rights and opinion is more stressed than others, i.e. when deciding joint custody and access to children, during an investigation regarding child abuse by the social services

\textsuperscript{83} The Data Inspection Board: Consent
(Chapter 1, Section 2 SOL), and in the interaction between the healthcare professionals and a child (Section 2g HSL). When looking at children rights on a national level, we’ll shortly discover that they often lie in the division between civil law and public law. The division between civil law and public law is very interesting to analyse and is somewhat central when discussing how a child using a patient support system can claim the rights to privacy on Genia Space. Can a child become a contracting party when agreeing to the terms of Genia? Swedish legislation says that a child under the age of 18 has no legal competence to make such commitments and undertake obligations, although there are some exceptions. It is generally up to the parents to make such a decision and entering contract on behalf of the child.

While the child’s encounter with healthcare is regulated under public law, the child’s rights concerning i.e. entering of an agreement concern his capacity to contract, and thus is regulated by civil law. A child has legal capacity, but not full legal competence. Every physical person, from the moment it is born until it dies, is recognised as an entity, allowing the individual to own property, have debts etc. An entity has legal capacity, making it possible to have rights and obligations and the ability to be a part of a judicial process (Swe., partshabilitet), not to be confused with legal competence. The general rule is that an individual with legal capacity also has full legal competence, but a child has not since it is a minor. A nine-year old has legal capacity to own a house, but not the ability to preform i.e. to sell or accept the house as a gift, due to the lack legal competence. A child has no legal right to undertake obligations on its own. But the older the children gets the more legal capacity is given and by the age of sixteen, the legal competence give them the ability to manage their own salary, Chapter 9, Section 3 FB. This is why a child cannot agree on the terms and conditions and become a party of an agreement by a provider on their own, the parents must agree on behalf of a child. A child could agree to the terms and conditions but there can be no consequences for the child if it breaches a contract. Why would this be important? If a child who uses a patient support system wants to protect his or her personal integrity by keeping certain

84 Schiratzki (2014) p. 19
85 Ramberg p. 54-56
infor
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private from parents, it is vital to examine if a child could achieve that on its own through contract law. In Sweden, it would not be probable since the target group of children in this thesis are at the ages of 9-14. The age limit might change in the future, as the children get more used to Internet-based services at an early age and have better understanding of such services. Even though it is a rule of thumb, the child will probably not have the legal capacity to consent to a provider’s terms and conditions that allows the child to have privacy in the app and thus, the privacy achieved by a child, aged 9-14, through contract law is not probable. Privacy can only be achieved through parents’ interference.
5 Children’s right to integrity

Nowadays, children are exposed to the Internet more than ever, making them accustomed to communication through Internet-based services, and users of social media and apps at a young age. Children in the Western World are born in a time where the Internet is a big part of society and social life. Through social media, sites or apps to connect with other people, such as Facebook, Twitter and Instagram, the users, including children, are connecting with together people around the globe through a personal profile. It is space that is considered to be a private sphere, a personal account that is displaying parts of ones private life.

Genia Space allows a digital space where children can chat with other children. It provides platform that enables connection to others that have the same struggle in life, where they can share experiences and motivate one another. The freedom to express and communicate with others sometimes includes some privacy from parents. From a child’s perspective, it can important to have a little space of privacy, especially when talking and sharing experience and emotions with other children who many times have had the similar challenges. The question is if a child has the right to hinder parents from using Genia Space?

5.1 Children’s rights

For more than a quarter of a century, the United Nations Convention on the Rights of the Child (UNCRC) has, on a global scale, influenced, changed and shaped children’s rights and living conditions all over the world. The convention is somewhat of a ‘Northern star’ for the world’s countries, a guiding-star for the goal and major task of securing and guaranteeing the child’s rights on a global scale. The convention is according to UNICEF the most rapidly and widely ratified international human rights treaty in history.\(^8^6\) There are current-
ly 194 countries that are parties to the treaty, all UN members, except for Somalia and America that has yet to ratify it. Ever since the UNCRC was ratified in Sweden in 1990, the efforts of underlining and bringing forth the child’s rights in legal areas, including their right to their own integrity, have been more intense and the work unceasing. In a letter to the Parliament, the Government revealed how it intends to continue to pursue the strategic work of the implementation. Also, the Swedish Parliamentary Ombudsman for Children have been given a key role in pursuing the implementation, including monitoring the compliance, of the UNCRC. The definition of a child, in Article 1 UNCRC, is not an entirely exhausting rule since it refers to domestic law and allows member states to intervene with their own definition of a child.

“For the purposes of the present Convention, a child means every human being below the age of eighteen years unless under the law applicable to the child, majority is attained earlier.”

The general rule, according to Swedish legislation, is that a child stops being a child the day he or she turns eighteen years old. The child’s rights are in some legal areas stronger than others because it is seen as more important to preserve. The third Article UNCRC state,

“The best interests of children must be the primary concern in making decisions that may affect them. All adults should do what is best for children. When adults make decisions, they should think about how their decisions will affect children. This particularly applies to budget, policy and law makers.”

The third Article UNCRC primarily points at the measures taken by the states government because it is the Government and its bodies that are constrained by the Convention. However, the Article should also apply to parents. The parents should think about the how their decision would affect the children and to

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87 Ewerlöf et al., p. 22
88 Skr. 2003/04:47
89 UNCRC Article 1
90 UNCRC Article 18 & Schiratzki (2013) p. 76-77
do what is best for them according to Article 18 UNCRC.\textsuperscript{91} The child’s best is a legal ambition that has central for a decision to meet the child’s different needs and interests.\textsuperscript{92} Children who wish to have some privacy and the desire to have a private sphere on a patient support system is most definitely something that parents must consider and take into account.

The child’s best interest is also defined on a national level. However, the notion and opinion on what a child’s right is differs from one legal area to another. Also, the diversity is shown in the implementation and prospect to argument for children’s right in different areas of the law.\textsuperscript{93} For instance the pre-work of LVU state that a child is to be regarded as an independent from parents and other family members.\textsuperscript{94} As previously mentioned, a child aged 9-14 will probably not have the right according to Swedish law to enter contract and agreeing to terms and conditions that allows a child to have that privacy through contract law. Instead, the child’s right to integrity will be examined through public law, mainly FB. FB is quite central since it regulates children’s right to integrity towards parents.

5.2 Children’s right to integrity increases with age and maturity

Children’s right to integrity in national Swedish legislation is foremost regulated in FB which states that the child has the right to its integrity and that is vital in order for a child to learn to make his or her own decisions, the child must get a fair chance to influence his or her own situation and the parents ought to encourage the child’s ability and will to express his or her wishes. However, it does not mean that parents always have to practise children’s expressed wish and will.\textsuperscript{95} Also, parents should not give the child the right to make all the

\textsuperscript{91} UNCRC Article 18  
\textsuperscript{92} Singer p. 34  
\textsuperscript{93} Schiratzki (2014) p. 36  
\textsuperscript{94} Schiratzki (2014) p. 34  
\textsuperscript{95} Olsen p. 185
decisions.\textsuperscript{96}

The parental duty, which is regulated throughout FB, continues until the day that the child turns 18, Chapter 6, Section 2 FB. It is also the parental duty that justifies their right of determination (Swe., bestämmanderätt) over a child.\textsuperscript{97} Parents have the right to represent the child in matters where that representation is not specifically regulated by legislation, such as representation by social services according LVU, i.e. Section 6.\textsuperscript{98} Children’s right to self-determination and the ability to act independent is limited.\textsuperscript{99}

According to the first sentence of Section 11 of Chapter 6 FB, the parental duty presumes that parents have an insight to the child’s life and business.\textsuperscript{100} The legislator has at the same time clarified that children have a right to their own integrity and that parents must recognise their opinion and wishes, which is interpreted as a child’s right to co-determination.\textsuperscript{101} The influence of a child in the family is regulated in the second sentence of Section 11 of Chapter 6 FB and is based on general principles. The general principles have no great legal significance other than bestowing a long-term impact on parents and legal guardians.\textsuperscript{102} Even though it has not the legal significance as with other regulations, the parents a responsibility for the child and includes making decisions based on what’s best for the child, Article 18 UNCHR is the central point of UNCHR.\textsuperscript{103}

According to the second sentence of Section 11 of Chapter 6 FB, a child’s right to integrity increases with age. Although the Act states that the child has the right to integrity as they develop but age is not defined in the Act, hence the uncertainty of at what age child has the right to integrity. However it does not eliminate the parent’s obligation towards the child and, to provide and protect the child. At the same time the regulation states that a child’s right to integrity

\textsuperscript{96} Ewerlöf et al., p. 31
\textsuperscript{97} Schiratzki (2013) p. 77
\textsuperscript{98} Schiratzki (2013) p. 53, 78
\textsuperscript{99} Schiratzki (2013) p. 51
\textsuperscript{100} Prop. 1988/98:67 p. 36
\textsuperscript{101} Schiratzki (2013) p. 61
\textsuperscript{102} Prop. 1981/82:168 p.88
\textsuperscript{103} Söderbäck p. 130
must increase with age and maturity. As a child grows and matures, they develop a need for liberating itself from the parents. Children’s liberation from the parents could mean having their own space, to make their own decisions and parents granting them an appropriate degree of privacy. The liberation is crucial step towards becoming an independent individual, hence the importance of the parents acceptance of it. The legislator not established a certain age of when a child has reached “the right age” and that is why the question of maturity must be decided on an individual basis. In theory, the will of a child could in some aspects be in a conflict with the parental duty. The complexity of balancing and handling these interests are vital when developing a patient support system that focus on children and in creating a platform from where children can interact and communicate with other individuals with the same disease.

Although Swedish legislation clearly states that a child has a right to integrity and also manifested Articles throughout UNCRC, the right is not hands-on because it is too vague and unclear. The legislation cannot answer the question on when a child is mature enough to have the right to integrity. Since there is not much guidance in the legislation and, case law regarding patient support systems and the issue about children’s right to integrity is almost non-existent, the thesis will look at past decisions and case law on healthcare. Even if the resemblance is not great between, the children’s wish to exclude parents from insight and information in patient support system and the healthcare, it is nonetheless, interesting to see at what age a child is considered to have attained maturity. Although a service such as Genia Space does not necessarily have to do with health-related information, even though children may discuss health-related issues it with other children, the healthcare and its case law can shed a light onto children as co-decision makers and their self determination which in this thesis is viewed as part of their integrity.

104 Ewerlöf et al., p. 31
5.3 Analogy between healthcare and patient support system

Given that there is not much guidance in case law to be found in this area, an analogy with the healthcare and its case law is at hand. The analogy aims at elucidate problems that occur and the complexity of the child’s will and co-decision right but also the pursuit of implementing the child’s rights into healthcare. Even though the case law will not cover the scenario where a child wants to keep some information to itself in a patient support system, it will be interesting to see how the conflict between children’s and parents’ will is discussed and what case law has brought with into this field.

When the law is unclear, children’s need of protection and support may not be met and furthermore that their integrity will be violated. The uncertainty of the legislation regarding when a child is mature is also noticeable within healthcare. In an earlier Government bill, the former Government shed a light onto the challenging conflict between the parental duty and the right to the child’s own integrity, affirming that the parental right decreases as the child gets older. In healthcare, it means i.e. that the parents cannot always access the child’s health records that are confidential without the child’s consent.

A report in 2008 addressed to the Parliament by the Swedish National Council on Medical Ethics (Swe., Statens medicinsk-etiska råd), pointed out in that the rights of children, as patients, are almost invisible in current legislation that is governing the healthcare. This has caused the Government to commence a research and discuss the issue in, for example prop. 2013/14:106, the new Patient Data Act that came into force 1st of January 2015. The Government bill on the Patient Data Act has shed a light onto the questions regarding children’s rights to integrity, including their right to self-determination and as co-decision makers, and also the protection of their integrity. Depending on the type of procedure and the situation, and maturity, a child can decide to commence a

106 Söderbäck p.14
107 Prop. 1988/89:67 p. 36-37
108 Skr. Children’s position within healthcare
procedure on its own even though the healthcare professionals are advised on striving towards making parents involved.\textsuperscript{109} Weakness of integrity is a consequence of children’s limited self-determination.\textsuperscript{110}

In a Government Official Report concerning patients’ judicial position, it was stated that parents normally have the right to make decisions in issues that are related to a child’s personal matter, which is referring to the parental right in FB. Nevertheless, when a child has reached a certain level of maturity but is not considered adequate or competent enough to make decisions, consent is needed from both child and parents.\textsuperscript{111} The problem of deciding at what age a child reaches the level of maturity to make own decisions has to do with the risk of making children undertake great responsibility when they are not mature enough, whilst other children can be refused the right self determination regarding decisions they are mature enough to make.\textsuperscript{112} To decide an age for when a child’s reaches maturity within healthcare is very complicated. It is stressed once again, in a recent Government bill that the level of maturity is individual and differs from one child to another. However, the Data Inspection Board’s rule of thumb, that a 15 year old has reached that level of maturity, is also shared with the Government.\textsuperscript{113}

The healthcare deals not only with at what age the child reaches maturity and all issues related to that but there is also a difference between a child’s positive bestämmanderätt (Eng., positive right of determination), the right to apply for a procedure, and negativ bestämmanderätt (Eng., negative right of determination), that a child alternatives to a certain procedure are cut down to two.\textsuperscript{114} Even though different types of right to determination have not been discussed, it is worth mentioning to give an idea of the questions complexity the health providers has to deal with.

\textsuperscript{109} Prop. 2013/14:106 p. 63-66
\textsuperscript{110} Bischofberger p. 39
\textsuperscript{111} SOU 1997:154 p. 60-61
\textsuperscript{112} Prop. 2013/14:106 p. 67, Söderbäck p. 125-126 & Skr. Children’s position within healthcare
\textsuperscript{114} Svensson p. 871 & Schiratzki (2013) p. 60
5.3.1 Case law

It seems to be somewhat problematic to draw the line between the child’s right to its own integrity, right to self-determination and co-determination, and the parents’ obligation and right to raise the child.\textsuperscript{115} There is an immense risk for division between a child’s wish and sense of integrity and the parental duty, which presumes a right to insight into a child’s business, which often leads to demarcation problems.\textsuperscript{116} This difficulty is shown more explicit in case law where issues regarding children’s will and integrity are in conflict with the parents will and right to insight into the child’s privacy. The decisions on whether or not the healthcare to waiver the confidentiality of a child, seem to depend on different variables.\textsuperscript{117} Sensitive information of a child could be kept confidential if there is an assumption that the child will suffer significantly if such information is disclosed to the parents, Chapter 12, Section 3 clause 1 OSL. It is not enough to keep information confidential from parents if a child thinks that the parents will undertake certain measures that the child does not approve of or that a child finds it unpleasant if the information is to be disclosed to the parents.\textsuperscript{118}

The Parliamentary Ombudsmen (JO) has in a decision\textsuperscript{119} spoken out about the prescription of contraceptive pills to a thirteen-year-old girl. JO stated that it would hardly be reasonable to demand to inform the parents or legal guardian when a seventeen-year-old wishes to get contraceptive pills prescribed to her. A seventeen-year-old child is considered to have reached that level of maturity FB describes, but not a thirteen year old. A child at the age of 13 is not considered mature enough to deal with a decision and the consequences of taking contraceptive pills. It would considered to appropriate to inform the parents so that they parents can address with issue with her.\textsuperscript{120}

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\textsuperscript{115} Schiratzki (2013) p. 60-61
\textsuperscript{117} Prop. 1998/99 p. 468
\textsuperscript{118} Prop. 2013/14:106 p. 69 & prop. 1988/89:67 p. 38
\textsuperscript{119} JO 1992/93 p. 439 ff.
\textsuperscript{120} JO 1992/93 p. 441-442 & Socialstyrelsen, Nr. 7/2010 p. 2
\end{flushleft}
According to a statement in a Government bill, children who reach their teens have reached the level of maturity and ought to have some protection of their integrity towards parents. But Socialstyrelsen (Eng., the National Board of Health and Welfare) objects to parents being deprived of such information that is important in order for them to fulfil their parental duty and to provide for the child.

Another sensitive situation is when a child, under the age of 15, gets pregnant. The Swedish abortion law does not set a minimum age for abortion; it only says that a woman have a right to do it, Section 1 (Abortlag (1974:595)). In theory, a child can have an abortion but, as in the case with the contraceptive pills, it conflicts with the parental right to insight into the child’s privacy. JO criticised the school of an 11-year-old girl who got pregnant for not disclosing information about the matter to the Social Services. An 11-year-old child is obviously not mature enough to understand the consequences of abortion on her own. Jo also commented on the matter of the absence of age in the Abortion Act, stating that absence of age regulation does not mean that authority can neglect the child’s age.

Case law does not bring enough clarity as to when a child is mature enough to have the right to their own integrity and the right to decide on matters. It does not give clear guidance on when a child has reached an age where the right to integrity is obtained. Nonetheless, the level of maturity of a child seems to depend on different variables such as the age, matter of subject, the procedure and the consequences of a decision. However, the case law does not address questions outside the healthcare and nevertheless, a provider of a patient support system. To simply apply the reasoning and thinking within healthcare directly on the situation that might emerge between a child and parents regarding a patient support system, when discussing exclusion from a platform for interaction, is neither optimal nor satisfactory. It does, however, shed a light on a complicated issue and the difficulty to draw the line between a child’s right to

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121 Prop. 1988/89:67 p. 36
122 Prop. 1998/99 p. 468
integrity and parents’ right to insight. Case law on this area has shown that a child’s interest, will and right to integrity will not always outweigh the parental duty.

5.4 **Children’s ability to exclude parents on legal grounds**

The decisions made by JO,\(^{125}\) are guidelines but it is important to remember that children’s maturity must be determined individually because children’s situation and circumstances may differ from one another. The case law illustrates that there are some health related matters children don’t want to share with parents, but rather wanting to keep it private. The legislation and the Government bill\(^{126}\) aims at describing the healthcare and the professional’s role and how they, according to law, must work with children. During the pre-work for the new Patient Act that came in to force 1\(^{st}\) January 2015, the Government discussed the rights of the child within the healthcare that would be affected, and proposed ways on how to be more aware when encountering a child and how to implement the child’s right into the Act in a more effective way.\(^{127}\) We can see that the consciousness towards the child’s best and will still continues and can be seen in government bills, regulations, policies and guidelines.

Due to the fact that Genia Space is not connected to healthcare professionals and not directly to healthcare, the case law cannot apply directly to the child’s privacy on Genia Space. A child’s wish and need to exclude parents from the Genia Space to have some privacy would perhaps be compared to keeping a diary or letters of correspondence with friends and not wanting parents to read it. The law does not give a child the right to stop parents from participating and have an insight to a child’s life, including a platform for interaction that is not connected to healthcare. It is not likely that the legislator wants to protect the child’s integrity to this level, and forbid parents from reading diary or letters. To go as far as to say that a parent has no right to read conversations a child

\(^{126}\) Prop. 1988/89:67
\(^{127}\) Prop. 2013/14:106
has with together children or hinder them to get insight to the child’s private life, including digital private space, would not be a rational conclusion. There has to be more at stake to waive the parents’ right to insight into the child’s private life other than simply reading a child’s thoughts and correspondence on the chat. The prohibition of the parents’ insight could be possible if crime has been committed and the social services take away the child and put it into foster care. That way, the parents could lose their parental duty. Even though a child has the right of co-determination and the UNCRC states that a child’s voice and will should be heard and be taken into consideration when parents are making decisions, to say that a child has the right to exclude parents from a platform for interaction or networking service is not probable. Even though a child has reached an age where it is considered to be mature and thus, have the right to integrity, it would not mean that the child has a right to exclude parents from insight to a platform for interaction, such as Genia Space. The child’s wish to privacy would probably not be a right that the legislator finds is worth preserving. However, their will and wish should be seen as children’s plea and has to be taken under consideration. If there is no legal ground for the child to proclaim its rights to privacy towards the parent, can the parents and the provider do something to give the child the private sphere?
6 Parents and provider’s collaboration

Although a child cannot exclude parents from Genia Space, perhaps the parents and the provider could arrange something to establish privacy on the platform. Parents could agree to give children private space by giving consent to the provider not to have the app version that includes Genia Space but register for an alternative version where Genia Space is not accessible. This would mean that provider and parents could collaborate, and the provider can present safeguard measures to meet the parents’ need for securing children and to strengthen children’s right to their integrity.

6.1 Children’s need for privacy

Today, children use social networking websites and apps more than ever and create their own profiles. Social media offer platforms through which interaction can take place, such as Facebook, Instagram and Twitter but they often have age restrictions. Facebook, amongst other apps and sites, requires that a user must be at least 13 years old before creating an account. A survey conducted by the Swedish Media Council showed that 68% of the children in the survey aged 9-13, had Facebook-accounts. The percentage was even higher for older children aged 13–16 and the results showed that 96% had Facebook-accounts. A recent report was conducted by OfCom on behalf of the UK Communications Act 2003 on the media use on children in the UK and it showed a lower frequency use compared to Swedish children. Only 28% of 9-10 year olds had social networking profiles and 59% for 11-12 year olds. The report also suggests that the age limit that has been set out by the apps and sites, such as 13, is not followed in reality. The children under 13 years create fake accounts by lying about their age in order to access the networking services.

128 Facebook: report a child under 13
129 Swedish Media Council: Youngsters and media, p. 9, 42
130 Media use and attitude reports 2014, p. 8, 21
There are certain risks involved when children create fake accounts on Facebook and other apps and sites, because they have not reached the age limit. Parents’ may worry about children being bullied, exposed, taken advantage of, grooming, self-harm and suicide-related content. A child is most likely to share very sensitive and private information, such as photos, phone numbers and address, and falls for group pressure that inflicts bad influence on the child. Not only does parents need to know that their children use Facebook but also understand and talk to the children about the dangers on social media. It is not unlikely that children hide the fake accounts from their parents. If children create fake accounts to interact with others, then surely we can see that there is a need for interaction, and social media seems to be our modern tool for it. The creating of fake accounts could also point towards a desire to create a space where a child can communicate with friends and discuss things through i.e. chats or by sending private messages. But desire to interact is perhaps even more for children with Cystic Fibrosis who cannot meet up with other children who have gotten the same diagnose because of risk of cross infection.

In a study, carried out by Palmer & Boisen in 2002, the participants, who had Cystic Fibrosis, reported that they felt that they had to avoid certain places and environments, making them feel that it constrained their social life. Their life is in some way limited as to where to go and who to meet because of their disease. Since patients with Cystic Fibrosis seem to feel that their social life is constrained, a patient support system with a networking service, such as Genia Space, could provide with a community in which they can “meet”, interact with others and find support. The study indicates that the patients are missing out on some parts of the social life and that is a key factor to why patients’ support systems could play a part in tomorrow’s modern healthcare. The opportunity to communicate with other patients, share experiences, daily struggles and encourage one another would seem to be beneficial to them. The digital meeting with other children with could contribute to a lot of things, i.e. motivation, advise on training and treatment, support in their daily struggles in

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131 The Guardian  
132 Forbes  
133 Palmer p. 45-58
schools, with friends and family and nonetheless, other children’s behaviour towards the child. There are also experiences and situations a child goes through that are sensitive to a child, for instance that they feel different or cannot do the things other children do due to their disease. This is sensitive information and it is important to give children, especially when they are reaching their teens, their space to share these experiences and situations with others. Children may not always want to talk about awkward questions or experiences with their parents but rather with a friend that has gone or is going through the same thing. That is why it would be proper for parents to give a child that space in the open by agreeing to it and giving the provider their consent to be excluded from Genia Space. This way a child has the parents’ consent that is based on trust, understanding and openness.

6.2 Parents’ consent

The privacy could be granted to the children by the parents’ who give their consent to it. The provider can through a type of policy-making gather the parents’ consent by getting their approval of the terms and conditions when they first register for a Genia-account. The consent would amount in parents using another version of Genia that does not contain the function Genia Space and hence wont get the insight to the child’s activity on Genia Space. Parents would probably legitimatise their consent for instance with an electronic signature, such as BankID. By doing so, the parent can give their consent to the provider to give the child another version that includes Genia Space. Besides agreeing to the child having one version and the parents another, the parents, on the behalf of the child, also agrees to the process of the child’s personal data on Genia Space. This is done even regardless because to process the personal data of a child, under 15 years of age, the parents would have to give consent to it. As with the information collected when first creating an account, the user’s personal data in the community cloud Genia Space is processed, making it the responsibility of the controller of personal data. As mentioned earlier, consent can be withdrawn at any time, Section 12 PUL.
Even though there are no legal actions for the child to take on when a parent withdraws the consent, there is a widely acknowledged principal called *til-litsprincipen* (Eng., principle of trust), which most probably is the common ground on which the consent is given. Presumably, both parties, child and parents, want to give the child the privacy and that is an indication of parents interest in keeping the agreement. This type of agreement could be described as one that is built on trust and other social factors, such as the relationship between a child and its parents, which might be of an immense emotional value. Based on the relationship and the trust that is at stake, the agreement between parents and child, although none binding in legal sense, could very well accomplish the wanted effect: to keep the agreement. Although the principle is only recognised as a guideline, it could have the cultural and social impact on the agreement and amount in parents not withdraw their consent unless the there is a suspicion that the child’s well-being is at risk. However, parents would presumably want to ensure their children’s safety and want reassurance that the children wont be bullied, exposed etc. The provider could meet the parents’ distress and request by establishing safeguard measures to secure the child’s integrity and safety on Genia Space.

### 6.3 Provider’s safeguard measures

There is no legislation that stipulates that a provider must specifically have the interest of the child in mind but in reality, a company whose focus group is a child will have the child’s best interest to reach and attract its target group. A company who provides a patient support system for and wants children to use it but will not adapt the service to the children would probably not be as successful. A way of establishing the privacy a child wants in Genia Space has to, as mentioned in previous chapter, involve a child’s parents. The provider could write the terms and conditions in such way that it includes parents’ approval and consent to let the provider manage privacy for a child on Genia Space if the child and parents wants to. Even though not every child wants this kind of privacy from its parents this could be a solution for those children who do want some privacy.
As previously mentioned, the provider could launch an alternative version of Genia for the parents without the Genia Space-function. However, it is pres-
sumable that all parents’ want safety of their child and would probably feel
distressed not to have an access, insight, to the child’s activity on Genia Space.
There are several apps, such as the app Mamabear, that focus on this issue
about the parents’ insight to the child’s activity on social networking apps and
sites. The app enables parents to monitor the child’s activity, for instance on
Facebook, to ensure safety. Although the thesis is not focusing on parents
monitoring the child directly, the need for reassurance of the child’s safety and
well-being on Genia Space could be achieved in a different way.

The provider of the patient support system can implement safeguard measures
to ensure children’s security and integrity. To give the parents the assurance of
the child’s safety, the provider could introduce a policy document that the child
must agree to follow to be able to use Genia Space. The policy can be de-
scribed as code of conducts or rules where certain rules of behaviour are
stressed and has to be followed by the users in the virtual community. The
child’s approval of the policy does not have any legal significance other than to
follow social rules such as, not allowed to: bully anyone, use strong language
etc. By accepting the policy in Genia Space, the child is obliged to follow the
rules. To implement the rules and to get the children to participate and approve
of the policy, the provider could do interviews with the children at the clinics
or through questionnaire. The policy could perhaps even be the result that is
solely based on thoughts and inputs by the children.

Another safeguard measure to ensure the integrity of children and decrease the
risk of harm is through a type of supervision. The question of responsibility of
supervision of Genia Space is a great challenge. The provider could accommo-
date the service with a moderator to ensure that the policy that the community
has approved of is being followed. This would however not mean that it would
override the controller’s responsibility of the information according to PUL.

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134 Mamabear  
135 Forbes
The controller would still process information in the community cloud and be held responsible according to PUL. The provider could introduce a safeguard measure for both parents and child by supplying Genia Space with a moderator, also called admin. The moderator could be an older person with Cystic Fibrosis, perhaps an older teen who is mature to take on the responsibility of monitoring, that supervises the service and who gives warning or excluding a child if it breaks the rules. The moderator would be monitoring on voluntarily basis. This idea could be compared to a closed Facebook group where admin has set out the terms of joining the group and allows him or her to exclude a member that is not following the rules. The monitoring of the children’s private messages is not that easy and would not be possible.

The provider’s safeguard measures, policy and supervision, and the collaboration with parents can be a solution in giving children the requested privacy on Genia Space.
Summary

Healthcare is now facing an era where new technology that can lead to new learning, take a natural place in the everyday life. It is a movement towards giving patients a more active role in their recovery and/or daily care of their disease.\textsuperscript{136} That includes new inventions such as patient support systems for patients with the need to monitor their health. In dealing with patients, especially children and information that is health-related and sensitive, the questions about their integrity are of great importance. The questions in the thesis are quite important to examine and comprehend because a child’s integrity has several aspects to it.

A provider of a patient support system must fulfil the requirements set in the legislation regarding the personal data about a user that is processed. Both Directive 95/46 and PUL, along with Government bills and Swedish Government Official Reports, states that there is responsibility for handling personal data, for instance through a patient support system. PUL addresses the responsibility to a controller of personal in Section 3 PUL that is the one who decides the purpose and means of processing personal data.\textsuperscript{137} There are a numbers of fundamental rules in Section 9 a-i, to guide the controller of personal data, and also other criteria stated in PUL for a controller of personal data to follow and adapt to. A patient support system that has the same structure as Genia, divided into two models and uses the concept of a private account, where the user is the only one who can access the information through private cloud, is probably excluded from the provision of the PUL. This is due to information is saved in the private cloud and is seen as a process of private nature Section 6 PUL resulting in the controller of personal data not being responsible for that process of personal data. On the other hand, personal information that is processed, such as the community cloud Genia Space, is a responsibility of the controller. The responsibility can also be shifted onto healthcare if information from a user is sent to a care provider.

\textsuperscript{136} SOU 2013:2, p. 76
\textsuperscript{137} SOU 1997:39 p. 333
The children today can download a lot of social networking apps such as Instagram, Facebook and Twitter and many of the children are creating fake accounts because of the age limits that are set by the social networks. Children seem to have the need to be on social media and communicating with others. The interaction with others is perhaps even more important for children with Cystic Fibrosis because of the risks involved in meeting others with the same disease. A patient support system with a platform for interaction with others in the same position could be a good tool for virtual meetings. There is a possibility that children from the ages 9-14 have developed a sense of integrity and maturity and wants to have some privacy when it comes to issues related to their health. Although the Parental Code states in second sentence of Section 11 of Chapter 6 FB states that a child’s right to integrity increases with age and maturity, the legislator has not defined at what age a child reaches that level of maturity. There is therefore no profound legal ground on which a child can stand and claim its right to integrity. The uncertainty of the timing of a child’s integrity seem to be blur even within the healthcare.

Case law is lacking in the area of patient support systems but in the area of healthcare, it has shown that there can be division between the child’s wish and sense of integrity and the parental duty that presumes a right to insight into the child’s business. The different interests regarding disclosure of a child’s health records to parents seem to be evaluated, and a decision on disclosure is made depending on the seriousness and the risk of a disclosure harming a child. The probability for a child to have a right to exclude parents from functions on a patient support system such as Genia Space is minimal. It would most probably be compared to a child having a right to prevent parents from reading its diary. However, the thesis suggests an alternative to give a child that kind of privacy and it entails collaboration between parents and provider.

In order to meet some children’s need and desire to privacy in Genia Space a solutions could be to establish an agreement between the parents and the child based on a mutual understanding of the privacy, assisted by a provider. Parents

can give their consent to a provider to exclude them from using the same version of the app as the child that includes Genia Space. The provider would instead launch an alternative version of Genia for the parents without the platform. A provider, who has parents’ consent, can offer the safeguard measures: policy and supervision. There would be a moderator who supervises the platform and the children’s activity on Genia Space.

As children mature and are exposed to a virtual world where social networking play a natural part of their daily life, it is vital to address their request for privacy, but foremost to find a solution. The safeguard measures are not given solutions but a result of answers to the questions, how to make it possible for children to get some privacy and how it can be achieved with the help of parents and provider. Generally speaking, it is better to communicate and for children to be open with their parents than the opposite and that is why the thesis is discussing the parents’ role. Even though this idea might not be the best solution or that it has many flaws, it is nevertheless a stepping-stone. To come up with a suggestion and to try to apply it to a real situation is all part of learning and coming one step closer to the right solution. This is my small contribution to it. Perhaps the children of tomorrow and parents will have a better understanding of social networking and have more experience in coping with issues related to privacy. It is even possible that safeguard measures wont be relevant in the future and that legislation is more clear and detailed regarding children’s right to privacy in patient support systems. Until then, we ought to remain and address questions that involve the integrity of children with diseases, who are extra vulnerable individuals, when using patient support systems. The new wave of patient-driven health care is on our doorstep, and it seems it is here to stay.
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**Directive**

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