

## **ANED 2014 Task 4 - Accessibility of Healthcare**

**Country:** Spain

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The <u>Academic Network of European Disability experts</u> (ANED) was established by the European Commission in 2008 to provide scientific support and advice for its disability policy Unit. In particular, the activities of the Network will support the future development of the EU Disability Action Plan and practical implementation of the United Nations Convention on the Rights of Disabled People.

This country report has been prepared as input for the synthesis report on <u>Access of healthcare</u> in European Countries.







## 1 Accessibility of Medical records which Patients are Entitled to Access

### 1.1 Obligations and Standards

# 1.1.1 Mandatory/Binding Accessibility Requirements applicable to Medical Health Records

There are no specific requirements, given that general accessibility requirements are mandatory since the Law 51/2003 of 2 December on equal opportunities, non-discrimination and universal accessibility for people with disabilities. Concerning health issues, every patient has the right to receive information on their health and access to medical records, as well to obtain a copy of the data. The State and the Autonomous Communities should guarantee access to these records to users with disabilities (Law 41/2002). Previous laws have been adapted to the EU and Spanish legislation on accessibility. For example, the Law 14/1986 of 25 April, on General Health states that every patient has the right to receive information about the health services they can access and the necessary requirements for use. The information must be made in appropriate formats, following the rules set by the design for all principle, so that they are accessible and understandable to people with disabilities.

Law 16/2003 of 28 May<sup>3</sup> on the Cohesion and Quality of the National Health System mandates coordination of the electronic interchange mechanisms for clinical and individual health information in order to allow access to both users and professionals under conditions that are strictly necessary to ensure the quality of healthcare and the information's confidentiality and integrity. Furthermore, the third additional provision of Law 41/2002 of 14 November,<sup>4</sup> the Basic Law Governing Patient Autonomy, states that that, "The Ministry of Health and Consumer Affairs in coordination with the regional authorities having competencies on the matter shall promote, with the participation of all stakeholders and in keeping with the evolution and availability of technical resources, the diversity of systems and the kinds of health records, the implementation of a system of compatibility to make its use possible by Spain's healthcare centres that care for the same patient in order to avoid those receiving treatment at different centres from being submitted to unnecessary repetitions of examinations and procedures". As a result, the Ministry of Health and Social Policy (MSPS) decided to tackle the National Health System

<sup>&</sup>lt;sup>4</sup> Act 41/2002, of 14 November 2002, basic regulating Act on the autonomy of the patient and on the rights and obligations in matters of clinical information and documentation. (Available in English: <a href="http://www.agpd.es/portalwebAGPD/english\_resources/regulations/common/pdfs/LEY\_DE\_AUTON\_DEL\_PACIENTE.pdf">http://www.agpd.es/portalwebAGPD/english\_resources/regulations/common/pdfs/LEY\_DE\_AUTON\_DEL\_PACIENTE.pdf</a>).





<sup>&</sup>lt;sup>1</sup> Act 41/2002, of 14 November 2002, basic regulating Act on the autonomy of the patient and on the rights and obligations in matters of clinical information and documentation. (Available in English: <a href="http://www.agpd.es/portalwebAGPD/english\_resources/regulations/common/pdfs/LEY\_DE\_AUTON\_DEL\_PACIENTE.pdf">http://www.agpd.es/portalwebAGPD/english\_resources/regulations/common/pdfs/LEY\_DE\_AUTON\_DEL\_PACIENTE.pdf</a>).

<sup>&</sup>lt;sup>2</sup> General Health Act 14/1986, available at: <a href="http://www.msssi.gob.es/organizacion/sns/planCalidadSNS/pdf/transparencia/Ley\_14\_86\_GRAL\_SAN">http://www.msssi.gob.es/organizacion/sns/planCalidadSNS/pdf/transparencia/Ley\_14\_86\_GRAL\_SAN</a> IDAD 1.pdf.

<sup>&</sup>lt;sup>3</sup> http://noticias.juridicas.com/base\_datos/Admin/l16-2003.html.



Electronic Health Records Project (HCDSNS) in 2006, as one of the cohesion instruments of the Spanish National Health System

# 1.1.2 Technical Accessibility Standards or Guidance relating to Medical/Health Records

There are no laws specific to accessibility on medical records, other than the general laws on Universal Accessibility requirements. However, since the interface for the HCDSNS is the Internet, the existing Web accessibility standards apply as well. Since access to medical records is through web pages and there are already rules for Web accessibility, there are no specific accessibility rules just for medical records.

# 1.1.3 Litigation or Other Publicly Documented Complaints about Inaccessible Medical Records

According to Spanish Law, complaints and claims can be submitted to the Permanent Specialised Office, the Ombudsman, and their counterparts at regional level, as well as to competent public authorities in regard to equal opportunities, nondiscrimination and universal accessibility for people with disabilities. In addition, and according to the General Law on Health, each Autonomous Community has its own Patient Advocate who is responsible for defending the rights of people in relation to their health. In exercising its functions, the Health Advocate may make proposals, recommendations and suggestions. Yet, in Spain, complaints are mostly related to violations of personal data protection, and the non-compliance with the Organic Law on Data Protection (LOPD).5 As an example, the HCDSNS system foresees the possibility of professionals accessing any information the patient may have decided to hide regarding any health reports comprising his/her electronic health records. In such a case, the professional has to leave evidence that the conditions allowing him/her to gain access to the information hidden by the patient have come about, leaving behind a trace of the instance of access that subsequently shows the citizen information concerning such access. The possibility of filing a complaint about any of the instances of access to the citizen's clinical data is also available. After selecting the instance of access about which the citizen wishes to file a complaint, he/she has to click on the information identifying the health service from which such access has been produced. A partially filled in form will be displayed (the citizen's identification data and details of the report about which he/she wishes to file a complaint) and then the citizen only has to fill in the sections on his/her address (postal or electronic address) where he/she wishes the response to be sent and the section aimed at reflecting the reasons for the complaint.

 $<sup>\</sup>underline{\text{http://www.agpd.es/portalwebAGPD/english\_resources/regulations/common/pdfs/reglamentolopd\_en.}}\\ \underline{\text{pdf-}}.$ 





<sup>&</sup>lt;sup>5</sup> ORGANIC LAW 15/1999 of 13 December on the Protection of Personal Data -English versión at: <a href="http://www.agpd.es/portalwebAGPD/english\_resources/regulations/common/pdfs/Ley\_Orgaica\_15-99\_ingles.pdf">http://www.agpd.es/portalwebAGPD/english\_resources/regulations/common/pdfs/Ley\_Orgaica\_15-99\_ingles.pdf</a>, and ROYAL DECREE 1720/2007, of 21 December, wich approves the regulation implementing Organic Law 15/1999, of 13 December, on the protection of personal data –English version at:



### 1.2 Accessibility of Medical Records in Practice

## 1.2.1 Extent of Accessibility

Although the possibility exists for citizens to access their medical records by the HCDSNS system, this is not widely known. The HCDSNS system (see: Health Information Institute (2011) NHS Electronic Health Record System. Madrid: Health Information Institute. It can be download from:

http://www.msssi.gob.es/organizacion/sns/planCalidadSNS/docs/HCDSNS English.pdf) aims: (1) to guarantee citizens' electronic access to their own health data and to the health data of those they represent that are available in digital format at any of the health services that make up the NHS, as long as they comply with the minimum security requirements laid down to protect their own data against illegal intrusion by those who have not been duly authorised to access such data. (2) To ensure the healthcare professionals duly authorised by each health service for such a function can access specific personal health data sets generated by a regional authority other than the one requiring the information, as long as the user or patient seeks the professional's healthcare services at a public NHS health centre. (3) To provide the NHS with a secure access system that guarantees citizens the confidentiality of their personal health data.

Accessibility in this regard is more associated to data security issues than to accommodations or Universal Design issues. "Security therefore plays an overriding role – given the system's criticality and the nature of the personal data processed by it – because such data require the highest level of protection set forth in the Organic Law on the Protection of Personal Data and the Royal Decree that develops it" (p.12)

#### 1.2.2 Good Practice Examples

The HCDSNS system is a good example by itself. It allows the citizens to (1) Query, print out or save any existing clinical reports on them; (2) Hide any clinical reports, which will not be displayed to the healthcare professionals that provide them with care. They will be aware that the citizen has decided to protect certain information, although they will not be informed what kind of information it is. (3) Query the instances of access that have been made to the clinical information (p.45).

### 1.3 Ongoing Developments

#### 1.3.1 Commitments to Improvement

At this point, there are two areas open to development and on which the efforts of all the players involved are focused: technical and semantic interoperability and the development of the HCDSNS system's pilot study, with a view to its subsequent implementation across the NHS.







## 1.3.2 Campaigns (eg by DPOs) or Calls (eg in academic publications) for **Accessible Medical Records**

Accessibility in this domain is related to Standards and Technical Requirements of the HCDSNS. Thus, there is a work group bringing together<sup>6</sup> a series of recommendations regarding: (a) the data interchange format (XML); (b) the formats of documents to be interchanged (PDF); (c) the image format (DICOM); (d) coding tables of the National Statistics Institute (INE) for regional authority, province, local authority, etc. codes; (e) unique patient identification through the Personal Identification Code; (f) identification of professionals (national ID card number (DNI)/national alien registration number (NIE)/passport number) or professional association membership number; (g) national alien registration number format; (h) security certificates; (i) interchange of clinical information (HL7 CDA level 1 for document headers). As explained earlier, medical records, as any other information to the patients, must be made in appropriate formats, following the rules set by the design for all principle, so that they are accessible and understandable to people with disabilities.

There have not been any campaigns by disabled people organizations about this issue.

## 1.4 Additional Information about the Accessibility of Medical Records

More detailed information on the access to electronic medical records can be obtained from this document (English Version): Health Information Institute (2011) NHS Electronic Health Record System. Madrid: Health Information Institute. It can be download from:

http://www.msssi.gob.es/organizacion/sns/planCalidadSNS/docs/HCDSNS English.p df

<sup>6</sup> Health Information Institute. NHS ELECTRONIC HEALTH RECORD SYSTEM (page 24). English version of the document available at: https://www.msssi.gob.es/organizacion/sns/planCalidadSNS/docs/HCDSNS\_English.pdf.





#### 2 Communications Between Medical Staff and Disabled Patients

### 2.1 Obligations and Standards

# 2.1.1 Mandatory/Binding Accessibility Requirements applicable to Relevant Communications

LAW 41/2002, of 14 November,<sup>7</sup> regulating patient autonomy and rights and obligations of clinical information and documentation, mandates that (fourth Additional Disposition): The State and the Autonomous Communities, shall adopt detailed regulations to guarantee patients or users with special needs related to disability, the rights to autonomy, clinical information and documentation covered by this Act.

Law 16/2003 of 28 May<sup>8</sup> on Cohesion and Quality of the National Health System provides in Article 28 that the accessibility of schools, health services and benefits for disabled people is a quality criterion to be guaranteed by the National Health System. The newly created health centres must comply with the rules in force in the promotion of accessibility and removal of barriers of all types that apply to them. The government must promote the removal of barriers in centres and health services that present obstacles for users with mobility or communication issues. Paragraph 2 of Article 3 of Law 16/2003, has been changed according to the Law 26/2011 of 1 August, for adaptation of laws to the International Convention on the Rights of Persons with Disabilities. Now, the paragraph states that the government will focus their actions on health incorporating active measures to prevent discrimination of any group of people who for cultural, linguistic, religious, social or disability reasons, find it particularly difficult to effectively access health services of the National Health System.

Royal Legislative Decree 1/2013, of 29 November, 10 approving the revised text of the General Law on the Rights of Persons with Disabilities and its social inclusion. Its Article 7, Right to equality, states that: (1) people with disabilities have the same rights as other citizens under our legal system. (2) In order to assert this right to equality, government measures to promote the exercise of equal rights of people with disability are real and effective in all areas of life. (3) The government particularly intensively protect the rights of persons with disabilities on equality between women and men, health, employment, social protection, education, fair hearing, mobility, communication, access to information and culture, sport, leisure and participation in public affairs, in the terms provided in this title and other regulations that may apply.

<sup>&</sup>lt;sup>10</sup> Available at: http://www.boe.es/boe/dias/2013/12/03/pdfs/BOE-A-2013-12632.pdf.





<sup>&</sup>lt;sup>7</sup> Act 41/2002, of 14 November 2002, basic regulating Act on the autonomy of the patient and on the rights and obligations in matters of clinical information and documentation. (Available in English: <a href="http://www.agpd.es/portalwebAGPD/english\_resources/regulations/common/pdfs/LEY\_DE\_AUTON\_D">http://www.agpd.es/portalwebAGPD/english\_resources/regulations/common/pdfs/LEY\_DE\_AUTON\_D</a> EL\_PACIENTE.pdf).

<sup>&</sup>lt;sup>8</sup> Updated versión available at: http://noticias.juridicas.com/base\_datos/Admin/I16-2003.html.

<sup>&</sup>lt;sup>9</sup> Available at: <a href="https://www.boe.es/boe/dias/2011/08/02/pdfs/BOE-A-2011-13241.pdf">https://www.boe.es/boe/dias/2011/08/02/pdfs/BOE-A-2011-13241.pdf</a>.



Its Article 10, Right to protection of health, states that the Government develops the necessary actions to promote access for persons with disabilities to services and health-related benefits equal to other citizens.

# 2.1.2 Technical Accessibility Standards or Guidance relating to Relevant Communications

Accessibility requirements are included in the Royal Decree 1494/2007 of 12 November, <sup>11</sup> approving the Regulation on access conditions of disabled people to the technologies, products and services related to information society and media services.

Under Spanish law, the websites of public bodies must meet appropriate standards of navigability and accessibility for people with disabilities. These standards are usually set by the W3C (World Wide Web Consortium) and are listed in: (1) Royal Decree 1494/2007, of 12 November<sup>12</sup> on the basic regulation for the access of persons with disabilities to the information society conditions. (2) UNE 139803:2012 Accessibility requirements for Web content.<sup>13</sup>

# 2.1.3 Litigation or Other Publicly Documented Complaints about Inaccessible Communications with Medical Staff

The Arbitration System on Disability, regulated by Law 51/2003,<sup>14</sup> is the instrument that the government made available to persons with disabilities to effectively resolve complaints and claims arising in the field of equal opportunities, non-discrimination and universal accessibility.

According to the Spanish Law, complaints and claims can be submitted to the Permanent Specialised Office, the Ombudsman, and their counterparts at regional level, as well as to competent public authorities in regard to equal opportunities, non-discrimination and universal accessibility for people with disabilities. In addition, and according to the General Law on Health, each Autonomous Community has its own Patient Advocate who is responsible for defending the rights of people in relation to their health.

To our knowledge, there have not been any registered complaints about inaccessible communications with medical staff.

http://www.msssi.gob.es/en/ssi/discapacidad/proteccionDerechos/sistemaArbitral.htm.





<sup>&</sup>lt;sup>11</sup> Available at: http://www.boe.es/boe/dias/2007/11/21/pdfs/A47567-47572.pdf.

<sup>&</sup>lt;sup>12</sup> Available at: http://www.boe.es/boe/dias/2007/11/21/pdfs/A47567-47572.pdf.

<sup>&</sup>lt;sup>13</sup> Available at: <a href="http://administracionelectronica.gob.es/PAe/accesibilidad/UNE139803=2012.pdf">http://administracionelectronica.gob.es/PAe/accesibilidad/UNE139803=2012.pdf</a>.

<sup>&</sup>lt;sup>14</sup> More information available at:



# 2.2 Accessibility of Communications with Medical Staff in Practice

## 2.2.1 Extent of Accessibility

Communications must be accessible, as explained above

### 2.2.2 Accessibility in the Training courses of Medical Staff

Royal Decree 1393/2007 of 29 October, <sup>15</sup> on the organisation of official university studies, provides for curricula to include, where appropriate, content related to the respect and promotion of human rights, and the principles of universal accessibility and design for all. However, as pointed out by Navarro et al. (2013) in his "New challenges for the future of the University: The integration of subjects on disability and universal accessibility in the training curriculum of current qualifications <sup>16</sup>", this requirement has not been met and 66 % of Spanish universities violate the decree, the only universities that meet 100% of the RD are a total of seven. In other words, although the degree in medicine, like all the degrees of the Spanish University, should include in their curricula content on universal accessibility and design for all, this does not happen in practice.

According to the "Survey on the degree of inclusion of the Spanish university system regarding the reality of disability" (Fundación Universia, 2013), 17 69 % of universities reported having included the variable disabilities in the design of new curricula. Inclusion is based on the incorporation of new content on caring for people with disabilities in the content and curricula. 17% of universities ensure that 100 % of the curriculum has considered this aspect, compared with 52 % of universities that said that, so far, it has only been included in some plans.

In the study published by the Ministry of Education: "The disability policy in the Spanish university system" (Rubiralta, 2011)<sup>18</sup> data revealed that such content or training has been incorporated into undergraduate studies in Architecture, mostly. These results are consistent with recent work (Navarro et al., 2013).

#### 2.2.3 Good Practice Examples

The Commission of the Conference of Rectors of Spanish Universities (CRUE) and Fundación ONCE,<sup>19</sup> are driving the program Universal Accessibility in the university education system. Its purpose is to provide new training content for a more

<sup>&</sup>lt;sup>19</sup>More information at: <a href="http://www.fundaciononce.es/noticia/la-fundacion-once-y-la-conferencia-de-rectores-de-universidades-espanolas-fomentaran-la">http://www.fundaciononce.es/noticia/la-fundacion-once-y-la-conferencia-de-rectores-de-universidades-espanolas-fomentaran-la</a>.





<sup>&</sup>lt;sup>15</sup> Available at: http://www.boe.es/boe/dias/2007/10/30/pdfs/A44037-44048.pdf.

<sup>&</sup>lt;sup>16</sup> Available at: <a href="http://web.ua.es/es/ice/jornadas-redes/documentos/2013-comunicaciones-orales/335237.pdf">http://web.ua.es/es/ice/jornadas-redes/documentos/2013-comunicaciones-orales/335237.pdf</a>.

<sup>&</sup>lt;sup>17</sup> Available at: http://www.fundacionuniversia.net/fichero?id=2110.

<sup>&</sup>lt;sup>18</sup> Available at: http://www.ikasleak.ehu.es/p202-

shdiscct/es/contenidos/informacion/dokumentuak/es\_document/adjuntos/Las%20pol%C3%ADticas%20de%20discapacidad%20en%20las%20universidades%20espa%C3%B1olas.pdf.



comprehensive training for professionals. The objective is to incorporate basic concepts in this field and provide a guide to good practice that promotes universal accessibility in the educational system, defining competencies, noting methodologies and educational activities, and opening lines of work, both in degree and postgraduate levels.

## 2.3 Ongoing Developments

### 2.3.1 Commitments to Improvement

Improvements need to be made concerning the implementation of existing measures.

# 2.3.2 Campaigns (eg by DPOs) or Calls (eg in academic publications) for Accessible Communications with Medical Staff

There have not been any campaigns so far.

# 2.4 Additional Information about the Accessibility of Communications with Medical Staff

There is no further information.







#### 3 Generic Health-Related Information

### 3.1 Obligations and Standards

# 3.1.1 Mandatory/Binding Accessibility Requirements applicable to Generic Health Information

According to the Transposition of Directive 2011/24/EU on the application of patients' rights in cross-border healthcare in national law (October 25, 2013), Spain has a registry of centres, services and establishments authorised by the Autonomous Communities which is available through the Ministry of Health, Social Services and Equality. The website of the Ministry offers information regarding the type of healthcare centers and services provided. The information contained in this register is updated periodically based on the data provided by the relevant bodies of the Autonomous Communities.

Currently, Spain has implemented several projects to strengthen the use of e-health tools and interoperable systems for health information. Last September, the Royal Decree amending Royal Decree 183/2004, which regulates the individual health card, which identifies users of the National Health System, was approved. This unique format of individual health card is another step for the full implementation of e-prescribing and interoperable electronic medical records; the most significant results are: currently 20 million Spaniards are already in the database of electronic medical records. Of these 20 million, 7.5 million have digital medical records shared with other countries of the European Union through the EPSOS project (http://www.epsos.eu/). Furthermore, 61.5 100 pharmaceutical prescriptions are issued and dispensed electronically and are adapted to European requirements. These e- health projects contribute to cooperation with other Member States and facilitate the spirit of the Directive 2011/24/EU, which is transposing.

To complete the transposition of the Directive 2011/24/EU, the Spanish legal system is in the final stage of the process to proceeding to immediate approval and publication, the draft Royal Decree establishing rules to ensure attendance relating to healthcare.

Finally, we note the existence of the National Contact Point (NCP)<sup>20</sup> established and based in the Ministry of Health, Social Services and Equality as the basis to ensure patients receive the information they need, in a transparent manner, about their rights in cross-border healthcare. The National Contact Point (PNC) will complement its information activity with units responsible for information of the Autonomous Communities and private healthcare providers. The information provided in that section must contain the following minimum elements: The list of centres and services offered, the applicable tariffs, the quality standards followed, the

http://www.msssi.gob.es/profesionales/saludPublica/sanidadExterior/RSI/Pdf/RSI\_2005\_ingles.pdf.





<sup>&</sup>lt;sup>20</sup> More information at:



authorisation procedure, and claims for reimbursement and the PNC contact with the other Member States to be established if a Spanish insured individual requires treatment in another member State. Spain has established a procedure to ensure a clear and consistent response to the request or demand for information from people within the framework of the Directive on cross-border healthcare.

As explained sbove, general accessibility requirements are mandatory since the Law 51/2003 of 2 December on equal opportunities, non-discrimination and universal accessibility for people with disabilities. Concerning health issues, every patient has the right to receive information on their health and access to medical records, as well to obtain a copy of these data. The State and the Autonomous Communities must guarantee access to these records to users with disabilities (Law 41/2002). Previous laws have been adapted to the EU and Spanish legislation on accessibility. For example, the Law 14/1986 of 25 April, on General Health states that every patient has the right to receive information about the health services they can access and the necessary requirements for use. The information must be made in appropriate formats, following the rules set by the design for all principle, so that they are accessible and understandable to people with disabilities.

# 3.1.2 Technical Accessibility Standards or Guidance relating to Generic Health Information

As explained above, there are no laws specific to accessibility of Generic Health Information, other than the general laws on Universal Accessibility requirements. However, since the interface for the HCDSNS is the Internet, the existing Web accessibility standards apply. Since access to medical records is throughout web pages and there are already rules for Web accessibility, there are not specific accessibility rules for Generic Health Information.

# 3.1.3 Litigation or Other Publicly Documented Complaints about Inaccessible Generic Health-Related Information

As explained above, the Arbitration System on Disability, regulated by Law 51/2003, is the instrument that the government made available to persons with disabilities to effectively resolve complaints and claims arising in the field of equal opportunities, non-discrimination and universal accessibility.

## 3.2 Accessibility of Generic Health Information in Practice

#### 3.2.1 Extent of Accessibility

The Ministry of Health, Social Services and Equality has established the National Contact Point that can be accessed from: <a href="http://www.msssi.gob.es/pnc/home.htm">http://www.msssi.gob.es/pnc/home.htm</a>. PDF, and mp4 formats are provided, but no easy read formats. Web Page accessibility is required for any official web page and this web page includes information on accessibility as well: <a href="http://www.msssi.gob.es/accesibilidad/home.htm">http://www.msssi.gob.es/accesibilidad/home.htm</a>







### 3.2.2 Good Practice Examples

The Ministry of Health and Social Policy (MSPS) has developed the National Health System Electronic Health Records Project (HCDSNS) in 2006, as one of the cohesion instruments of the Spanish National Health System.

The HCDSNS system (see: Health Information Institute (2011) NHS Electronic Health Record System. Madrid: Health Information Institute. It can be download from: <a href="http://www.msssi.gob.es/organizacion/sns/planCalidadSNS/docs/HCDSNS">http://www.msssi.gob.es/organizacion/sns/planCalidadSNS/docs/HCDSNS</a> English.p df) aims: (1) to guarantee citizens' electronic access to their own health data and to the health data of those they represent that are available in digital format at any of the health services that make up the NHS, as long as they comply with the minimum security requirements laid down to protect their own data against illegal intrusion by those who have not been duly authorised to access such data. (2) To ensure the healthcare professionals duly authorised by each health service for such a function can access specific personal health data sets generated by a regional authority other than the one requiring the information, as long as the user or patient seeks the professional's healthcare services at a public NHS health centre. (3) To provide the NHS with a secure access system that guarantees citizens the confidentiality of their personal health data.

Accessibility in this regard is more associated to data security issues than to accommodations or Universal Design issues. "Security therefore plays an overriding role – given the system's criticality and the nature of the personal data processed by it – because such data require the highest level of protection set forth in the Organic Law on the Protection of Personal Data and the Royal Decree that develops it" (p.12).

## 3.3 Ongoing Developments

#### 3.3.1 Commitments to Improvement

As previously mentioned a report by the Health Information Institute states (<a href="http://www.msssi.gob.es/organizacion/sns/planCalidadSNS/docs/HCDSNS\_English.pdf">http://www.msssi.gob.es/organizacion/sns/planCalidadSNS/docs/HCDSNS\_English.pdf</a>), that the responsibility of guaranteeing that each instance of access to the system meets the requirements lies with the regional authority to which the system's user is linked, either as a healthcare professional or as a citizen who is duly registered in the regional authority in question. The extent to which the system is implemented on each Autonomous Community is key to guaranteeing equal opportunities for any Spanish citizen.







# 3.3.2 Campaigns (eg by DPOs) or Calls (eg in academic publications) for Accessible Generic Health-Related Information

General accessibility requirements are mandatory since the Law 51/2003 of 2 December on equal opportunities, non-discrimination and universal accessibility for people with disabilities. Concerning health issues, every patient has the right to receive information on their health and access to medical records, as well to obtain a copy of the data. The State and the Autonomous Communities should guarantee access to these records to users with disabilities (Law 41/2002). <sup>21</sup>Yet, in Spain there have not been campaigns or calls for accessible generic health related information because concerns are mainly focused on confidentiality and security issues. As explained above, complaints are mostly related to violations of personal data protection, and the non-compliance with the Organic Law on Data Protection (LOPD). <sup>22</sup>

# 3.4 Additional Information about the Accessibility of Generic Health-Related Information

No further information.

 $<sup>\</sup>underline{http://www.agpd.es/portalwebAGPD/english\_resources/regulations/common/pdfs/reglamentolopd\_en.}\\ \underline{pdf-}\ .$ 





<sup>&</sup>lt;sup>21</sup> Act 41/2002, of 14 November 2002, basic regulating Act on the autonomy of the patient and on the rights and obligations in matters of clinical information and documentation. (Available in English: <a href="http://www.agpd.es/portalwebAGPD/english\_resources/regulations/common/pdfs/LEY\_DE\_AUTON\_D">http://www.agpd.es/portalwebAGPD/english\_resources/regulations/common/pdfs/LEY\_DE\_AUTON\_D</a> EL PACIENTE.pdf).

<sup>&</sup>lt;sup>22</sup> ORGANIC LAW 15/1999 of 13 December on the Protection of Personal Data -English versión at: <a href="http://www.agpd.es/portalwebAGPD/english\_resources/regulations/common/pdfs/Ley\_Orgaica\_15-99\_ingles.pdf">http://www.agpd.es/portalwebAGPD/english\_resources/regulations/common/pdfs/Ley\_Orgaica\_15-99\_ingles.pdf</a>, and ROYAL DECREE 1720/2007, of 21 December, which approves the regulation implementing Organic Law 15/1999, of 13 December, on the protection of personal data –English version at:



## 4 Medical Equipment

## 4.1 Obligations and Standards

# 4.1.1 Mandatory/Binding Accessibility Requirements applicable to Medical Equipment

On general accessibility, Royal Decree 505/2007, of 20 April,<sup>23</sup> accessibility and non-discrimination of persons with disabilities to access and use of public spaces and urbanised buildings regulates the basic conditions of accessibility in public buildings and urban spaces to ensure everyone has independent and safe use of them and in order to ensure equal opportunities and non-discrimination of people with disabilities.

More specifically, Article 10, Right to protection of health, of the Royal Legislative Decree 1/2013, of 29 November, <sup>24</sup> approving the revised text of the General Law on the Rights of Persons with Disabilities and its social inclusion is approved, states: the government will promote the necessary measures to facilitate access for people with disabilities to services and health-related benefits equal to other citizens. However, as indicated by González Carrasco (2013) in her paper: "Discrimination on grounds of disability in the private healthcare insurance" - available at: http://www.revista.uclm.es/index.php/cesco - " Article 10 sets out a general way, the principle of non-discrimination in access to health services, imposing on public authorities a duty to take steps to improve access for people with disabilities to services and services relating to your health on equal terms with other citizens. A specific regulation of the right of access to health insurance or assistance, according to the principle of non-discrimination is required. González Carrasco states that: "the situation of disabled people in relation to access to health insurance is particularly complex because the insurance market tends to confuse the existing situation regarding the "health" of the applicant with the situation of "disability" (p. 447). Article 23, Basic conditions of accessibility and non-discrimination, establishes the requirement for accessibility of buildings and environments, instruments, equipment and technologies, and goods and products used in the field or area. In particular, the removal of barriers to facilities and adaptation of equipment and instruments, as well as appropriate signage thereof.

This issue applies to accessibility requirements for medical equipment. That is, more specific regulations are required

# 4.1.2 Technical Accessibility Standards or Guidance relating to Medical Equipment

It is necessary to increase efforts to ensure the existence of accessible medical equipment in health services in primary care and specialized services. As Cayo

<sup>&</sup>lt;sup>24</sup> Available at: http://www.boe.es/boe/dias/2013/12/03/pdfs/BOE-A-2013-12632.pdf.



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<sup>&</sup>lt;sup>23</sup> English versión at: <a href="http://sid.usal.es/idocs/F3/LYN13770/LIONDAUbuildings.pdf">http://sid.usal.es/idocs/F3/LYN13770/LIONDAUbuildings.pdf</a>.



(2006) has suggested<sup>25</sup> more efforts should be made to ensure accessibility and design for all and the elimination of barriers of all kinds (physical, communication, understanding, mental, etc.) in buildings, centres, offices, facilities and procedures in the public health field.

In Spain there is no specific regulation that establish minimum technical criteria to ensure that medical equipment used for diagnostic purposes by health professionals in or in conjunction with physician's offices, clinics, emergency rooms, hospitals, and other medical settings is accessible to and usable by individuals with disabilities.

# 4.1.3 Litigation or Other Publicly Documented Complaints about Inaccessible Medical Equipment

Each autonomous community, and in consequence, each health administration has its own laws to regulate the right to exercise complaints and make suggestions in the field of health. The annual reports of health care includes, among other information, the Complaints and suggestions for User Health in Castilla y León. To our knowledge, these reports do not include complaints or claims related to accessibility issues. Yet, given the complexity of the Spanish health system, more information with common indicators across Autonomous Communities would be advisable in order to compare data and to further analyze specific complaints concerning these and other similar issues.

## 4.2 Accessibility of Medical Equipment in Practice

#### 4.2.1 Extent of Accessibility

It is necessary to increase efforts to ensure the existence of accessible medical equipment in health services in primary care and specialized services

#### 4.2.2 Good Practice Examples

More public information on good examples is required

#### 4.3 Ongoing Developments

## 4.3.1 Commitments to Improvement

Policy development is needed to ensure the full development of regulations on accessibility of medical equipment and services

<sup>&</sup>lt;sup>25</sup> See: http://www.feaps.org/biblioteca/documentos/asistencia\_sanitaria.pdf.



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# 4.3.2 Campaigns (eg by DPOs) or Calls (eg in academic publications) for Medical Equipment to be made Accessible

More campaigns and more visibility on the need for medical equipment to be accessible are required.

# 4.4 Additional Information about the Accessibility of Medical Equipment

There is no additional information available.







#### 5 Telemedicine Services

### 5.1 Obligations and Standards

# 5.1.1 Mandatory/Binding Accessibility Requirements applicable to Telemedicine Services

Telemedicine is quite new in Spain. Next we provide some basic background on the state of the art in this regard.

Health Online<sup>26</sup> is an integrated programme of the Avanza Plan, launched by the Government of Spain to accelerate the integration of Spain in the Information Society, increase productivity, strengthen the industrial sector of the Information Technology and Communication (ICT) to foster R & D and build modern, interoperable public services based on the effective use of ICT.

During the first phase of the Online Health Programme (2006-2010), the legal framework for joint work between the Ministry of Industry, Energy and Tourism - Red.es - through, and the Ministry of Health, Social Services and Equality was established, with the 17 autonomous communities and the National Institute of Health Management INGESA), responsible for public health care in the autonomous cities of Ceuta and Melilla. At the same time, during this first phase, the management model was structured to achieve the objectives.

Under this model, red.es managed different projects funded with investments from the Central Government and FEDER funds, while the Autonomous Communities executed their respective investments, financing activities within their Electronic Health Record project, online appointments, and ICT infrastructure. The Ministry of Health, Social Services and Equality coordinated state projects, as well as the expansion of the Central Node of the National Health System (NHS) and Electronic Medical Records project of the National Health System (HCDSNS). The execution was carried out in the period 2006-2010 and had a budget of 252 million euros, of which 140 million were provided by red.es, while the Ministry of Health, Social Services and Equality provided a million euros and the different Autonomous Communities provided 111 million Euros.

Key projects undertaken by red.es under the Online Health Program I (2006-2010<sup>27</sup>), were: (1) technological infrastructure and associated services to the Autonomous Communities. (2) The collaboration with the Ministry of Health, Social Services and Equality to achieve, first, the full synchronisation of a regional health Card Database Users of the National Health System; and second, the expansion and consolidation of a neutral node with high availability.

https://www.msssi.gob.es/profesionales/hcdsns/TICS/TICS\_SNS\_ACTUALIZACION\_ES\_2010.pdf.



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<sup>&</sup>lt;sup>26</sup> More information downloadable at:

https://www.msssi.gob.es/profesionales/hcdsns/TICS/TICS\_SNS\_ACTUALIZACION\_ES\_2010.pdf.

<sup>&</sup>lt;sup>27</sup> More information downloadable at:



The main results are summarised as follows: 6,565 beneficiary centres (hospitals, clinics, specialty centers ...) in which 102,771 were installed components (PCs, printers, monitors and servers). In addition 39,087,581 citizens and 327,535 professionals in health (doctors, nurses ...) know about the project.

# 5.1.2 Technical Accessibility Standards or Guidance relating to Telemedicine Services

As we have explained before, there are no specific requirements, given that general accessibility requirements are mandatory since the Law 51/2003 of 2 December on equal opportunities, non-discrimination and universal accessibility for people with disabilities.

Policy development is needed to ensure the full development of regulations on accessibility of Telemedicine services.

# 5.1.3 Litigation or Other Publicly Documented Complaints about Inaccessible Telemedicine Services

To our knowledge, there are no publicly documented complaints about Telemedicine, given that this is a very new service and it is not generally available.

## 5.2 Accessibility of Telemedicine Services in Practice

#### 5.2.1 Extent of Accessibility

Telemedicine is guite new and no information in this regard is available yet.

#### **5.2.2 Good Practice Examples**

Telemedicine is constantly present in the media, and relevant foundations, like Fundación Telefonica

(http://www.fundacion.telefonica.com/en/educacion\_innovacion/discapacidad/), and Fundación Vodafone (http://fundacionorange.es/index\_en.html) are developing relevant experiences and promoting its use by persons with disabilities.

There is also a centre CENTAC (<a href="www.centac.es">www.centac.es</a>.) dedicated to promoting the development of accessibility technology within the business, industry and services sectors, so as to facilitate access to the same and enhance the quality of life of the elderly and the *disabled*, as well as their families. This center has been "set up within the framework of integration and equality policies regarding the rights of all, irrespective of physical or social conditions". These policies have been undertaken by the various Regional Governments of Spain in recent years. CENTAC is an initiative developed by The Secretary of State for Social Services, Families and Disability, The Royal Disability Trust and The Secretary of State for Telecommunications and for the Information Society.







## 5.3 Ongoing Developments

### **5.3.1 Commitments to Improvement**

Government and private initiatives described may result in important advances in these years.

# 5.3.2 Campaigns (eg by DPOs) or Calls (eg in academic publications) for Accessible Telemedicine Services

In addition to actions of The Secretary of State for Social Services, Families and Disability and The Royal Disability Trust (like CENTAC),<sup>28</sup> Fundacion Telefonica and Fundacion Orange,<sup>29</sup> CERMI<sup>30</sup> (the Spanish Committee of Representatives of Persons with Disabilities) is organising acts and publishing reports related to this topic.. For example, the 'Spain 20.20. Report ICT and Sustainability ', conducted by the Club of Sustainability devotes an extensive section to telemedicine.<sup>31</sup> The report highlights that electronic administration facilitates access for people with disabilities to public administration. In this regard, the report states that the group of persons with disabilities has mentioned that this is one of the reasons for using the Internet. The Vodafone Foundation has undertaken the study 'access and use of ICT for people with disabilities'.<sup>32</sup> The study concludes that 32.9% of this group (which, like all chronic patients, is an important for health spending) use mobile phone systems that improve their quality of life and medical care.

#### 5.4 Additional Information about the Accessibility of Telemedicine Services

No additional information available.

#### References

epSOS – the European eHealth Project. Downloaded from: <a href="http://www.epsos.eu/">http://www.epsos.eu/</a>
Fundación Universia (2013). Universidad y discapacidad. Estudio sobre el grado de inclusión del sistema universitario español respecto de la realidad de la discapacidad. Author: Fundación Universia / Comité Español de Representantes de Personas con Discapacidad-CERMI. <a href="http://hdl.handle.net/11181/4142">http://hdl.handle.net/11181/4142</a>

Health Information Institute (2011) NHS Electronic Health Record System. Madrid: Health Information Institute. It can be download from: <a href="http://www.msssi.gob.es/organizacion/sns/planCalidadSNS/docs/HCDSNS\_English.pdf">http://www.msssi.gob.es/organizacion/sns/planCalidadSNS/docs/HCDSNS\_English.pdf</a>

Navarro, N., Muñoz, P., Sánchez, A. y Suarez, M. (2013). *Nuevos retos de futuro para la Universidad: La integración de asignaturas sobre discapacidad y* 

<sup>32</sup> http://fundacion.vodafone.es/static/fichero/pro\_ucm\_mgmt\_568168.pdf.





<sup>28</sup> http://www.centac.es/

<sup>29</sup> http://fundacionorange.es/.

<sup>30</sup> http://www.cermi.es/es-ES/Paginas/Portada.aspx.

http://www.clubsostenibilidad.org/f\_publicaciones/spain%202020%282%29.pdf.



accesibilidad universal en la formación curricular de las titulaciones actuales. XI Jornadas de Redes de Investigación en Docencia Universitaria, Universidad de Alicante. <a href="http://web.ua.es/es/ice/jornadas-redes/documentos/2013-comunicaciones-orales/335237.pdf">http://web.ua.es/es/ice/jornadas-redes/documentos/2013-comunicaciones-orales/335237.pdf</a>

- Organic Law on Data Protection (LOPD). English version can be accessed from: <a href="http://www.agpd.es/portalwebAGPD/english\_resources/regulations/common/pdfs/Ley\_Orgaica\_15-99\_ingles.pdf">http://www.agpd.es/portalwebAGPD/english\_resources/regulations/common/pdfs/Ley\_Orgaica\_15-99\_ingles.pdf</a>
- Royal Legislative Decree 1/2013 of 29 November (Official Gazette 3 December), consolidating the rights on people with disabilities (Mor information at: <a href="http://www.non-discrimination.net/content/media/ES-19-Disability%20Law.pdf">http://www.non-discrimination.net/content/media/ES-19-Disability%20Law.pdf</a>)
- Rubiralta, M. (2011). Las políticas sobre la discapacidad en el sistema universitario español. Madrid: Ministerio de Educación, Centro de Publicaciones. <a href="https://sede.educacion.gob.es/publiventa/detalle.action?cod=14911">https://sede.educacion.gob.es/publiventa/detalle.action?cod=14911</a>



