

Figure 1. Vee diagram showing both sides, conceptual and methodological, and highlighting the focus questions which will guide the project

The V diagram (Figure 1) has been designed in order to answer the following focus questions which represent the objectives of this work:

- Will this project promote awareness towards RD affected children in primary and secondary schools and contribute to a normalization process and an inclusive education?
- Will RD affected students learn how to use concept maps and design Knowledge models for promoting meaningful learning and for facilitating their curricular adaptation when being at home or in hospital?
- Will primary and secondary education students learn about the main characteristics of the RD their mates suffer?
- Will it be possible to create a bank or collection of RD KM through the different schools involved in the study to make them get known in Navarre?

Since the enactment of the 1989 Convention on the Rights of the Child (CRC), domestic legislation has been adapting to the principles contained in the Declaration. Although legislation and the legal system of each country might be different, 193 countries have been devoting

special measures for their protection, at the legislative and constitutional rights. Within the Rights of the Child four key principles are highlighted:

- (1) Non-discrimination: all children have the same rights.
- (2) The interests of the child: any decision, law, or policy that may affect the child has to take into account what is best for the child.
- (3) The right to life, survival and development: all children have the right to live and have a proper development.
- (4) Participation: minors have a right to be consulted on situations that affect them and their views must be taken into account.

By means of this proposal we pretend to give voice to RDAS and try to make them have the same opportunities as any other children to be educated and to live their lives from a wider perspective. In order to fulfill the four key principles of the Convention of the Rights of the Child (CRC), the construction of RD based KM is provided as a tool available to all children, schools, teachers, and involved educational agents. KM will be built by students and they are examples of meaningful learning and

knowledge creative cooperative construction [13,5].

3.2. Design of Knowledge Models (RDs) for Learning about RDs and Encouraging Social Awareness

For the proposal of the educational intervention to be carried out in different primary education schools in Navarre, UPNA’s teachers designed a general RD based KM to show the project’s final goals and the educational process to follow.

The root map of the KM titled “Educational intervention for RD affected children” (Figure 2), was designed for promoting the learning of RD, for showing the difficulties RDAS must confront throughout their whole life and for favoring social awareness.

However, the construction of the CM (some subordinated to others) is an iterative process in order to ensure thorough coverage of topic maps and faithful representation of expert knowledge [7, 8, 9]. Once constructed, required resources (photos, documents, videos, audio, Web pages, etc.) that best complement and explain the key concepts in CM must be selected.

This project will help in getting social awareness and meaningful and long life learning through the construction of Knowledge Models (KMs) and their design using CM.

The process of building a KM on “Rare Diseases in Navarre”, therefore, involves the problems of RDAS in the health, social and educational field, as shown below in Figure 3.

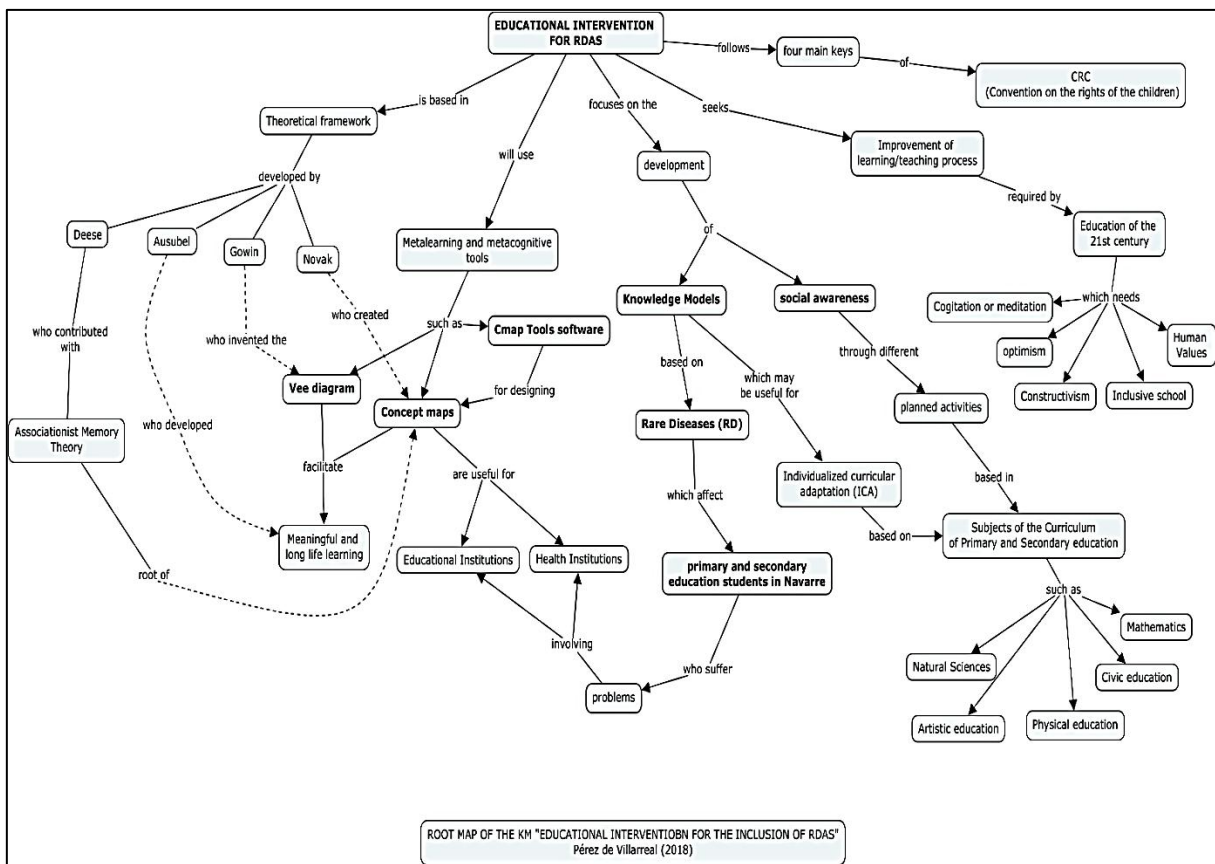


Figure 2. Root concept map of the KM entitled “Educational Intervention for RDSA”, which contains other subordinated maps which conform the KM and which can be used as interface.

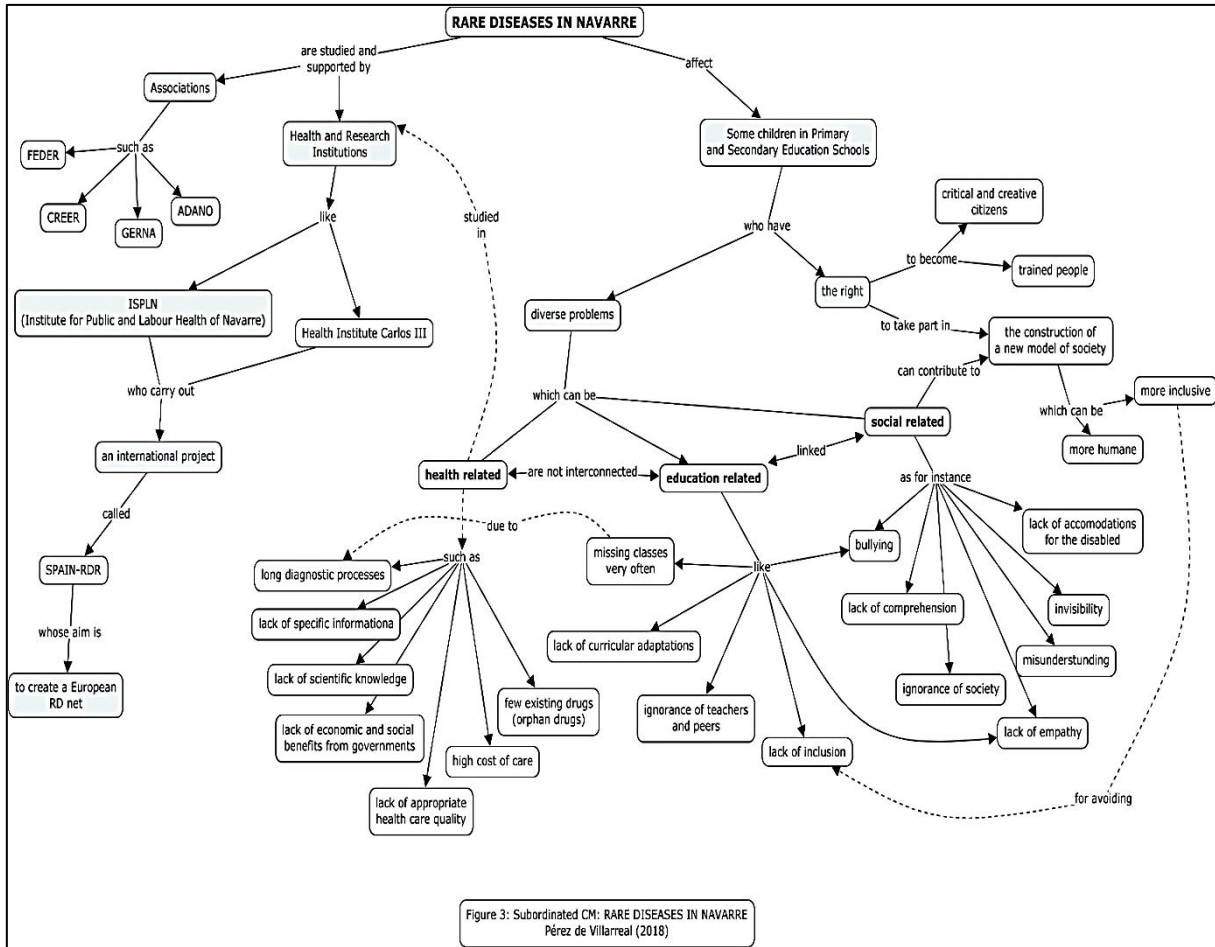


Figure 3. Subordinated concept map of the KM, titled “Rare Diseases in Navarre”.

This CM shows the right RD affected children have to become educated people and critical and creative citizens (goals of the Education of the XXI century) and to take part in the construction of a new model of society which must be more humane and more inclusive. These children also face several problems which can be health, education and society related. Among the problems related to the health field, it is mentioned, the lack of specific and helpful information, the long diagnostic processes, the lack of scientific information, the high cost of care and therapies...In the education related problems, it is pointed out, the missing of classes (due to the diagnostic processes

and the care and therapies), the lack of curricular adaptations, bullying, lack of inclusion...In the society related problems, it is noteworthy the invisibility, the lack of comprehension and empathy towards affected children and the ignorance.

In the next subordinated CM (Figure 4), the diagnosed Rare Diseases in Navarra which affect some children attending Primary education schools are shown. This CM can be useful for the final goal of the project, which consists in creating a bank or collection of KMs of the different Rare Diseases represented in Primary Schools of Navarre.

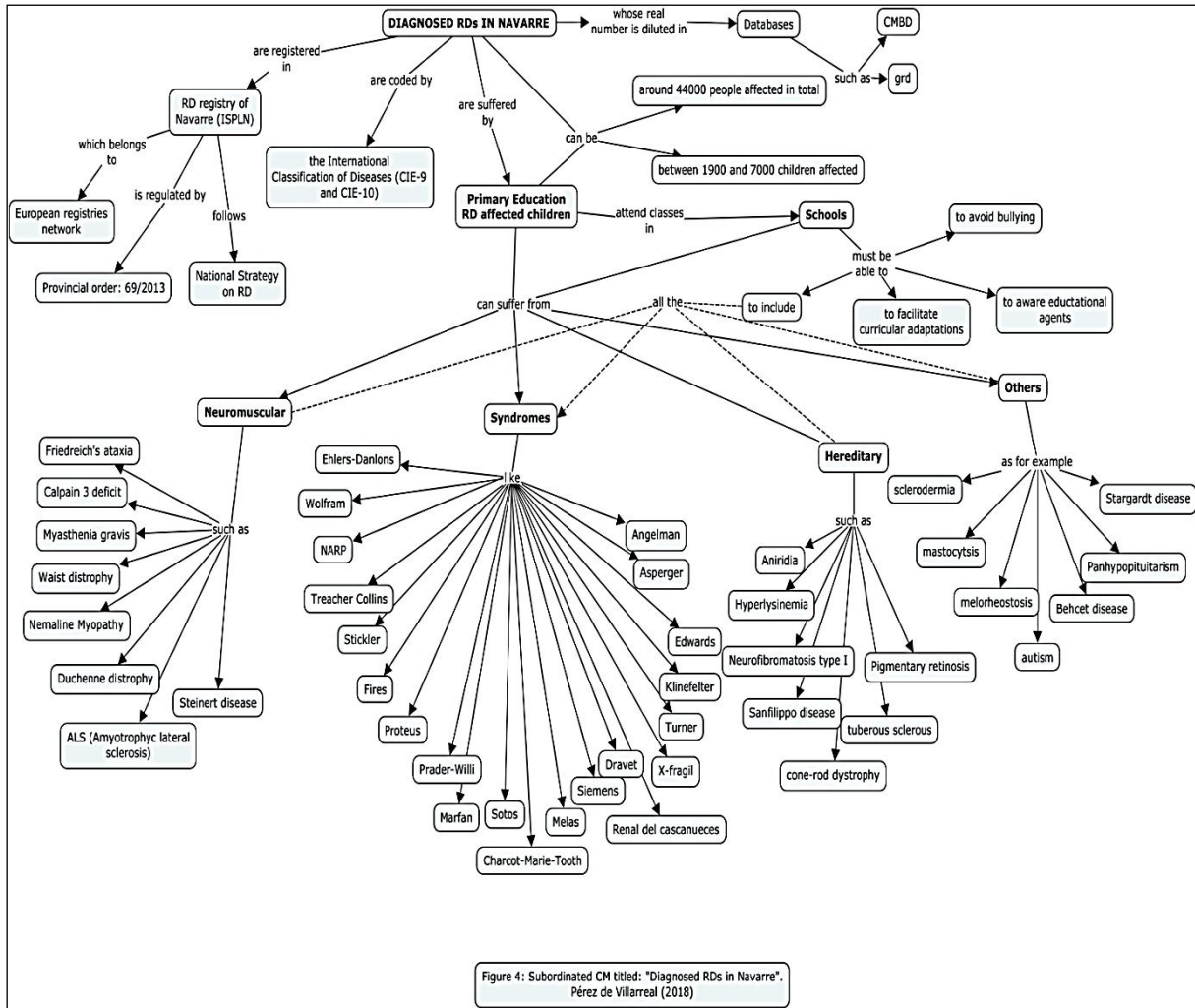


Figure 4: Subordinated CM titled: "Diagnosed RDs in Navarre". Pérez de Villarreal (2018)

Figure 4. Subordinated concept map of the KM, titled “Diagnosed RDs in Navarre”, which shows the different diagnosed RDs in Navarre and which can be represented in the different primary schools of Navarre, therefore providing information for developing KMs of the different RDs and contributing to create a bank of RDs KMs in Navarre.

To summarize, if clicking on the map from Figure 2, which represents the KM of the "Educational intervention for RD affected children" and contents the more general and inclusive concepts, we can use it as interface, being possible to navigate by clicking on the concept "Rare Diseases". This concept leads to the CM of Figure 3 “Rare Diseases in Navarre”. If clicking on the concept “Some primary education children of Navarre”, the CM of Figure 4 "Diagnosed RDs in Navarre" gets displayed. A number of details obtained by clicking the corresponding generic icons and graphics linked to concepts are also observed.

Through clicking on any of the RDs displayed, students can learn the main symptoms and characteristics of each disease. In each of the cases, in each school, they would learn about the disease affecting their peer but thanks to the bank of KMs they could also learn about the characteristics of other RDs affecting other Primary Education children in Navarre.

As an indication of protocol for any educational intervention with RD affected children, the following CM has been designed.

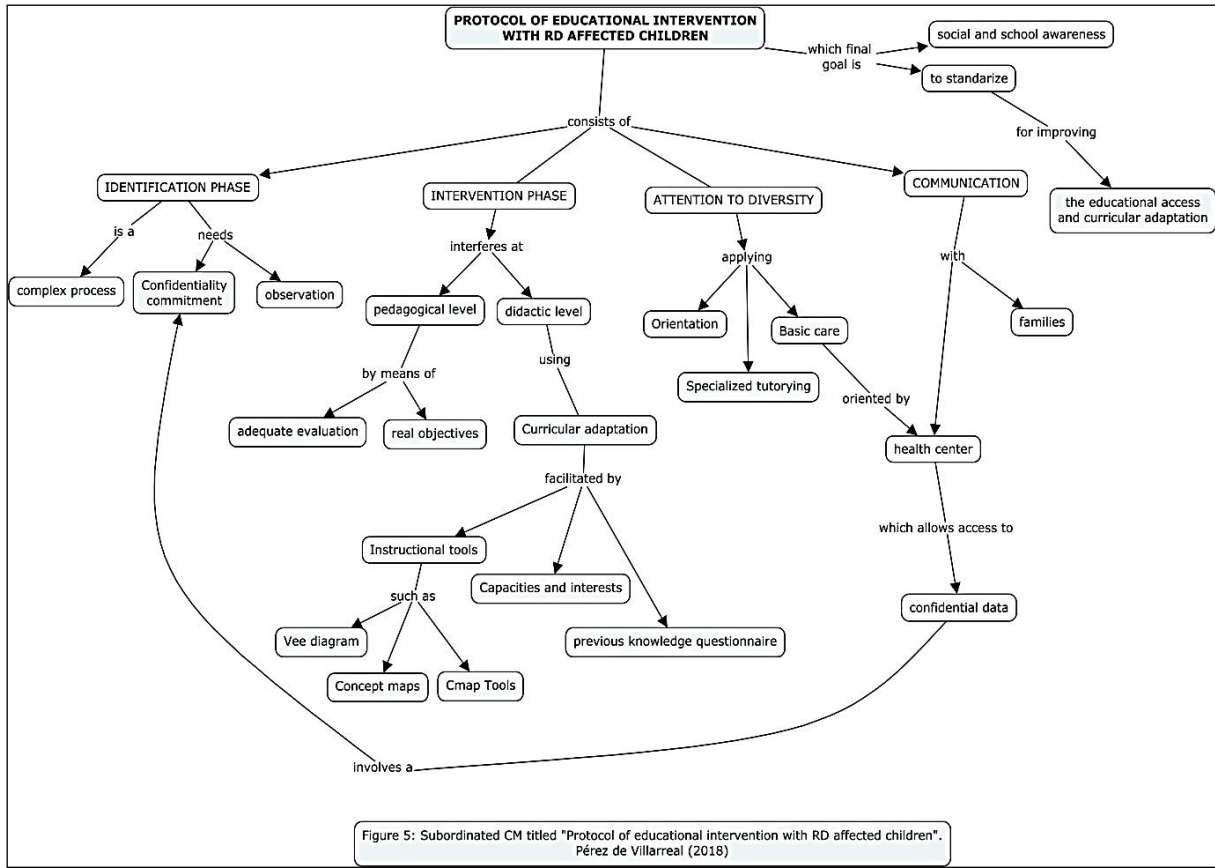


Figure 5. Concept map showing the protocol to follow for implementing the educational intervention in RDAS in order to standardize it in different schools in Navarre and to promote social awareness.

4. Discussion

UNESCO [26], states education is a fundamental human right, essential to exercise all other rights. It promotes freedom and personal autonomy generating significant benefits for one's development. However, millions of children and adults remain deprived of educational opportunities, in many cases because of poverty. However, there are also cases of education deprivation in developed countries. This is the case of disabled people, some of whom are RD affected, who miss classes frequently because of their health status. In this group, we would be talking about RDAS, who suffer the consequences of their health problems and hospital admissions and care therapies. However, in the most serious conditions, students cannot attend classes and therefore are in risk of getting out of the educational system. Only in the most fortunate cases but very infrequently, these students are subjected to individualized educational program (ACI) or curricular adaptations. It is up to governments to fulfill their obligations, both legal and policy reasons, relating to the provision of quality education for all and more effective implementation and monitoring of educational strategies. Through this article, we try to point out to the complicated world of RD and

those who suffer them, with special emphasis on the primary education affected children. Through an immediate need identified by the association GERNA [11] in different Primary Education schools in Navarre (Spain), a proposal of educational intervention was designed, which can become a bigger project and which can help improve the educational and social situation of RD affected children in the long term, helping to standardize a protocol and to aware society and school about the real problems these students have to face in their daily basis.

The Vee diagram [15] designed by UPNA's teachers identified the key issues that led to the birth of this proposal and some of the focus questions have been answered through this work but others still need future work to be done. Nevertheless, the first and most important step is that RDAS should be able to be identified in infant or primary education schools, as the vast majority may need curricular adaptations (CA) in their future, due to the difficult diagnostic processes and the long treatment periods in which they must miss school. These students are also susceptible of suffering bullying, especially in the cases in which their physical appearance is different. In order to avoid or minimize these problems, it is necessary to bear in mind these children are also members of our society and will be part of our future, and

we should provide them the tools to be included in an inclusive and egalitarian society; inclusion which must start in school and be reflected in society. In spite of the lifelong impact which many RDs entail and the beyond question complexity involved in many of these diseases, we have the moral duty of improving their education considering their right to be educated and take part of a changing society as human beings and develop themselves according to their possibilities, since there are some less serious conditions which are compatible with a better quality of life during childhood and youth. During this period and in cases in which students may attend classes (in person or virtually), we suggest the possibility of using ICTs (Technology of Information and Communication) such as the free software Cmap Tools (IHMC, Florida, USA). By using this tool we can facilitate their learning by creating knowledge models [13, 19], which may help them be more creative and feel more valuable for society, therefore increasing their self-esteem. Knowledge modelling is proposed as a methodology to be used in primary and secondary school for promoting meaningful learning, and also for encouraging their mates' awareness towards their difficult reality, fact that will spread later on in the whole society as it is a cultural and conceptual change which is being setting up. The intention is to implement instructional tools that could help RD affected students continue their education would also help the other students get to know about RDs and the reality affected people have to confront and accept and integrate RDAS as any other mate, normalizing their appearance and presence in class.

The main objective of this work in the long term, is to standardize a protocol to carry out educational interventions in primary and secondary schools, especially in some of the schools where RDAS study, and create banks of diagnosed Rare Diseases Knowledge Models which can be useful for other schools and other students in this or other countries. But particularly in this proposal, we show how to create KMs, based on information that the student must turn upon a previous assessment and transform it into substantive and useful knowledge into their cognitive structure. Each map contained in the KM, is derived from the foregoing, powering their own meanings. The KM is like a building which has been built based on meaningful learning and it is original, because although the information was there, reorganizing it and its consequent re-conceptualization has led to the development of an original model, open to any improvements, by some students able to add value to it with new information relevant to them and having an organized mind. CM helps identify, understand and organize the concepts we plan to teach and also help to specify the relationships (propositions) necessary for the understanding [13]. CM prepared by the student is an effective way of knowing what he/she already knows. As a key principle in education is to start considering what

the learner already knows, to investigate is a very important task in any educational initial step [22]. The use of CmapTools and the building of their own knowledge provide students with resources to acquire significant learning, change their cognitive structure at the time it energizes their learning, and enable them to adapt to the rest of the class, despite the abstention of school associated with their disease [23]. The experience of connecting new information to existing knowledge in a meaningful way [13], causes positive feelings on students, and when they recognize the change in their own cognitive structure, the meaning of this experience changes in a powerful and lasting way.

Through the educational intervention, students will get to know the characteristics of the main RDs in Navarre, especially the one affecting their mate, and once they know the difficulties RDAS confront because of their health, empathy arises and the bullying shadow starts disappearing. Further research is needed in order to confirm the possibility of using KMs and Vee diagrams as ICA (Individual Curricular Adaptation), but evidence to support these value judgments are the results of other investigations [2, 5, 22, 23]. The aim is that students achieve meaningful learning through the construction of KMs, based in the particular case of a RD affected mate in class. This way, students affected by RDs may continue the lessons, and the rest of the students, learn about the reality of their colleagues being more empathic, always taking into account a confidentiality commitment, in which only what the RDAS and their families agree to tell is used. Every student, enabled or disabled has the right to learn in a meaningful way for the rest of his/her life (Convention of the rights of the child, 1989). Finally, it is remarkable the fact that education is a powerful tool that allows children and adults who are socially and economically marginalized to go out of poverty through their own efforts and participate fully in the community life.

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