



# Implementation of an evaluation project of the Disabled People Care Network

## Implementação de um projeto de avaliação da Rede de Cuidados à Pessoa com Deficiência

## La implementación de un proyecto de evaluación de la Red de Atención de Personas con Discapacidad

*Andrezza Gonzalez Escarce\**  
*Amélia Augusta de Lima Friche\**  
*Roberta Alvarenga Reis\**  
*Mônica Farina Neves Santos\**  
*Gabriela Cintra Januário\**  
*Fernanda Jorge Maciel\**  
*Raimundo de Oliveira Neto\**  
*Stela Maris Aguiar Lemos\**

### **Abstract**

This study is aiming to describe the course taken by a team of researchers to elaborate and develop a research project to evaluate the Disabled People Care Network in the state of Minas Gerais. This is an

\*Federal University of Minas Gerais, Belo Horizonte, MG, Brazil.

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### **Authors' contributions:**

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RON: data analysis and interpretation, drafting and revision of the version to be published.

SMAL: study conception and design, data analysis and interpretation, drafting, revision and final approval of the version to be published.

**Correspondence address:** Andrezza Gonzalez Escarce - andrezza.ge@gmail.com

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experience report, in which the stages taken by the team were highlighted and the importance upon the discussion of the research topic, as well as the regular meetings occurrences; preliminary results based on the regarding the study of secondary data; the preparation of collection instruments; the selection of new members and holding the instrumentalization; the completion of the sample calculation and the pilot study. It is important to register the route taken in a way to allow new studies to replicate this process and thus generate the comparison with results in different scenarios.

**Keywords:** Methodology; Evaluation; Unified Health System; Health care.

## Resumo

O objetivo do estudo é descrever o percurso utilizado por uma equipe de pesquisadores para elaboração e desenvolvimento de um projeto de pesquisa para avaliação da Rede de Cuidados à Pessoa com Deficiência em Minas Gerais. Trata-se de relato de experiência, no qual foram destacadas as etapas percorridas pela equipe e a importância da discussão do tema da pesquisa, bem como a realização de reuniões periódicas; dos resultados preliminares com base no estudo dos dados secundários; da elaboração dos instrumentos de coleta; da seleção de novos integrantes e realização da instrumentalização; da realização do cálculo amostral e do estudo piloto. É de relevância o registro deste percurso para que novos estudos possam reproduzir este processo e, conseqüentemente, gerar a comparação com resultados obtidos em outros cenários.

**Palavras-chave:** Metodologia; Avaliação; Sistema Único de Saúde; Atenção à saúde.

## Resumén

El objetivo del estudio es describir el recorrido metodológico de un equipo de investigadores a planear y desarrollar un proyecto de investigación para evaluar la Red de cuidado de la persona con discapacidad en Minas Gerais. Se trata de un relato de experiencia, dividido por pasos. Fueron aspectos destacados en el manuscrito: las medidas tomadas por el equipo, la discusión del tema de la investigación, las reuniones periódicas; los resultados preliminares sobre la base del estudio de datos secundarios; el desarrollo de los instrumentos de recolecta de datos; la capacitación de nuevos miembros; la realización del cálculo de la muestra y un estudio piloto. Es importante registrar este camino para que nuevos estudios pueden replicar este proceso y por lo tanto generar la comparación con los resultados en otros contextos.

**Palabras claves:** Metodología; Evaluación; Sistema Único de Salud; Atención a la salud.

## Introduction

The World Health Organization (WHO), through the International Classification of Functioning, Disability and Health (CIF), defines disability as a problem in the functions or structures of the body<sup>1</sup>. Thus, the functionality becomes a protagonist rather than the disease, and the disability of the individuals is seen as an aspect of their relationship with their environment<sup>2-4</sup>.

According to the World Report on Disability<sup>5</sup> of 2012, 15.3% of the world population has some moderate or severe disability. In Brazil, there are different strategies for the identification of people with disabilities. The National Health Survey (PNS)<sup>6</sup>, with sample basis, found that 6.2% of the population had at least one of the investigated

disabilities, being the visual of higher incidence, followed by physical, auditory and intellectual disabilities. On the other side, in 2010, the Census of the Brazilian Institute of Geography and Statistics (IBGE)<sup>7</sup> found 23,9%.

Faced with this reality, in order to expand and qualify the care of people with temporary or permanent, progressive, regressive or stable, intermittent or continuous disabilities, in April 2012, the Ministry of Health established the Disabled People Care Network (RCPD) within the Unified Health System (SUS)<sup>8</sup>. Its actions are directed to people with hearing, physical and intellectual disabilities, ostomy and multiple disabilities<sup>8</sup>.

However, its construction deals with a complex process, often interspersed with socio-cultural and operational barriers. In addition, the expanded

concept of health associated with the principles of integrality, universality and decentralization proposed by the Unified Health System (SUS), make it essential to know the structure of this Network in the state spheres, aiming at the proper functioning of the entire system<sup>9</sup>.

Thus, it is important to contemplate the Network in all its complexity in the evaluation, and to approach the perceptions of managers, health professionals and users by different points of view, in order to contribute to the improvement of the Network and of the service provided. It is also worth noting the scarcity of evaluation methods and studies related to RCPD<sup>10,11</sup>.

In this context, the present communication is characterized as an experience report elaborated by the team of the research project entitled "Disabled People Care Network in Minas Gerais": population profile, and evaluation of the access and structure. Its purpose is to describe how to elaborate and develop a research project.

## Method

### *Study design*

This study was an observational analytic cross-sectional study, which purpose was to describe the construction process of the steps used to identify, know and evaluate the RCPD in the State of Minas Gerais from the perspective of service coordinators/managers, professionals and users, and to evaluate the structure of these services.

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### *Team members*

The team was composed by three professors of federal universities of the State of Minas Gerais and State of Rio Grande do Sul, two health managers of the Health Department of the State of Minas Gerais (SES/MG); an advisor of the general direction of the School of Public Health of Minas Gerais (ESP/MG), a professional of the Hearing Health Regulatory Board of Belo Horizonte/MG, a speech therapist, fellow of science and technology management of the project and six fellows, which were integrated to the project later.

### *Scenario of the study*

The scenario of the study is the RCPD of the State of Minas Gerais established in 2012<sup>12</sup>. The rehabilitation actions are taken in specialized units and the services are articulated among themselves, ensuring the integrality of access in each point of care<sup>13</sup>.

The State of Minas Gerais has 853 municipalities, distributed in 77 Health Regions, divided in 13 Expanded Health Regions<sup>14</sup>. In 2015, it had 209 registered services in all the Expanded Health Regions of the State, in different phases of implementation of a new Network, in a process of adjustment of the functioning and articulation among the services, according to the legislation in force<sup>8,12,13</sup>.

### *Design of the sample calculation and its results*

The analysis units defined were the Expanded Health Regions and the Health Regions according to the Regionalization Master Plan of the State of Minas Gerais, since this Plan serves as an organizational guideline for healthcare in the Unified Health System (SUS).

The points of care that compose the RCPD were the basis for the sample calculation in the State of Minas Gerais.

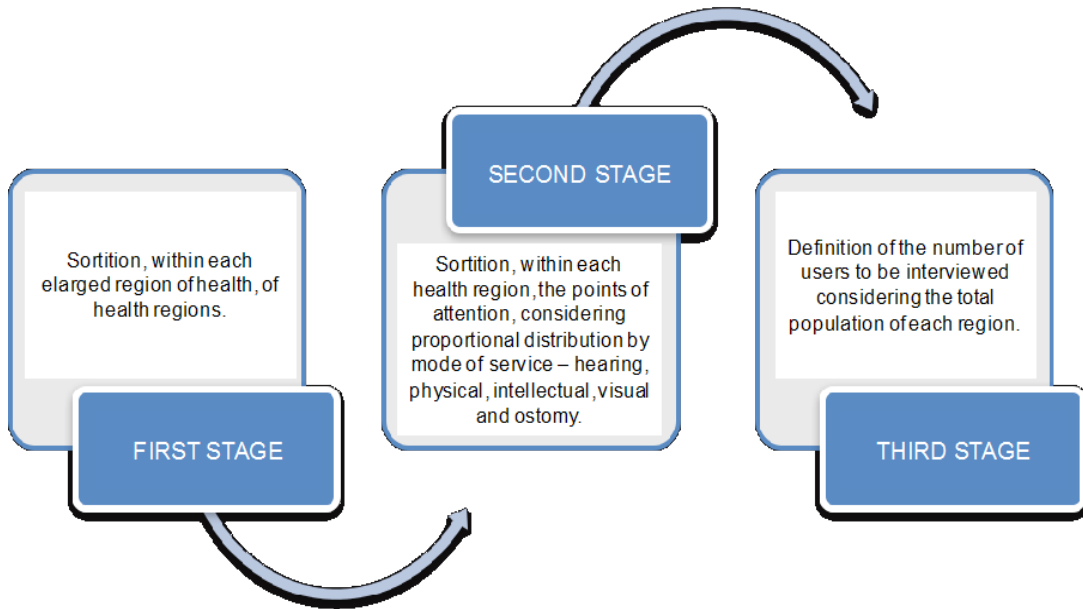
The random sampling was performed in three steps, stratified by the 13 expanded health regions and proportional to the population of each of them, as shown in Figure 1.

During the visit in each selected service, the users were randomly invited to participate. All professionals and managers present were also invited to participate in the study.

The following parameters were considered for the sample calculation: confidence level of 95%, margin of error of 5% and the prevalence of the variable of interest (disability) according to data from the Brazilian Census of 2010<sup>7</sup>, which was chosen since it is a research with the population universe and closer to the values reported in the World Report on Disability<sup>5</sup>.

Once the design of the sample calculation was defined, its analysis was performed using the proportion estimation method for finite populations<sup>15</sup>, with proportional allocation of the sample, first by the 13 expanded health regions, and later by the health region and type of service.

The sample size for estimation of proportions for finite populations is given by the expression



**Figure 1.** Stages of random sampling

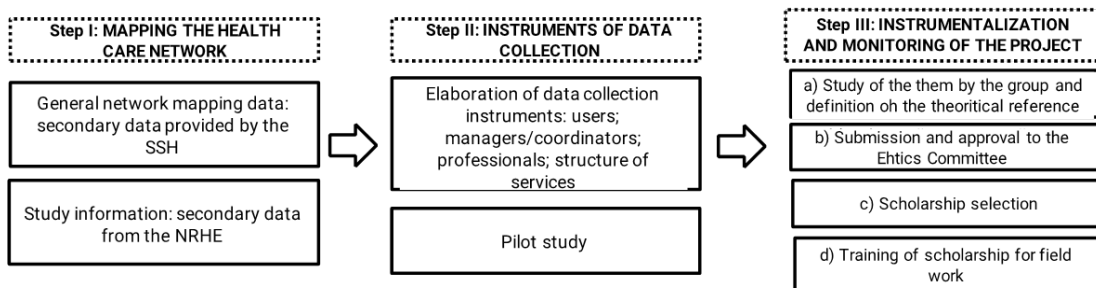
below, where  $\alpha$  represents the percentile of the normal distribution corresponding to the level of significance,  $\beta$  is the margin of error,  $N$  is the total size of the population with disabilities in the health regions and  $p$  some proportion of interest provided from the research instrument. Thus, considering the total population of 18,225,658 and the prevalence of 14% of people with disabilities, there is an  $N$  equal to 2,551,593, which represents the total population of people with disabilities in the State of Minas Gerais.

To enable the calculation of the sample size for the different variables with the significance levels

and margin of error specified, a  $p$  of 50% was used, which represents the prevalence. This choice is the maximum possible assumption and is justified as all the possibilities of the different variables are not known, since the sample size obtained on this assumption is maximum, sufficient for any possible result.

*Synthesis of the methodological path*

Figure 2 shows the synthesis of the methodological path used to design the research project.



**Figure 2.** Synthesis of the methodological course for the design of the research project

### Preliminary results

In the first step, the initial mapping of the RCPD was performed based on the analysis of the secondary data provided by SES/MG. The presence of points of care in all the territory of the State, the type of service offered and its relation with the population density were considered. For this purpose, the georeferencing of the points of care and geoprocessing techniques were carried out to describe the spatial distribution of the specialized care component, in accordance with the national and state legislation.

In addition to the data of the SES-MG, information from the National Register of Health Facilities CNES/DATASUS was used, related to the specialized component of the RCPD of the State of Minas Gerais. A total of 209 services were identified, distributed according to the modalities: intellectual disability rehabilitation service (63.6%), rehabilitation of the ostomy patient (13.9%), physical rehabilitation (8.6%), auditory

rehabilitation (6.2%), visual rehabilitation (1.4%) and centers specialized in rehabilitation (6.2%). In these services, there are 3.271 registered professionals to compose the minimum teams of each specialty. However, 17.7% of the services do not have a complete minimum team. In addition, it was observed that there is a greater number of equipment aimed at the care of people with intellectual disabilities (73.8%), besides a greater concentration of services in the South Health Expanded Region (29.7%).

In the next step, based on the compilation of theoretical references and data from RCPD, the group elaborated the collection instruments. It was agreed that the instruments should aim to evaluate the RCPD by the different actors and in different dimensions (assistance, management and structure). Thus, instruments were designed for conduction of interviews with users, managers/coordinators of the health services and professionals, as well as for analysis of the structure of the service. (Chart 1)

**Chart 1.** Collection instruments for the study on RCPD/MG and its objectives

Instrument	Axes and main items addressed	Type of elaboration
Users	Structured script to analyze the user perception and satisfaction with the services and the Network, according to the following thematic axes: a) sociodemographic and economic data; b) data of the caregiver/informant; c) characterization of the access, care path and use of the Network; d) satisfaction with the Network; e) objective evaluation of the satisfaction of the user.	Research team
Professionals	Structured script to analyze the perception of the professional regarding the implementation of the Disabled People Care Network in the region covered by the service in which it actuates, as well as its satisfaction, through the following thematic axes: a) sociodemographic and economic data; b) access; c) care routine; d) satisfaction with the service; e) human resources; e) participation in scientific events.	Research team
Service Manager/ Coordinator	Structured script to verify the perception of the manager/coordinator of the service regarding the following thematic axes: a) sociodemographic and economic data; b) satisfaction; c) positive and negative points of the service/Network.	Research team
Structure of the service	Structured observation script to be completed by the researchers during visits to the services for description and analysis of the structure of the points of care, verifying if the structure is according to the ordinance recommendation (reference ordinance). Its thematic axes will be: a) identification of the service; b) physical structure; c) equipment; d) human resources; e) service environment.	Research team
Evaluation of healthcare networks	Instrument proposed by Mendes <sup>16</sup> (2011) and published by the Ministry of Health.	Literature <sup>16</sup>

For calibration of the elaborated instruments and outline of the methodological choices, a pilot study was conducted at a randomly selected RCPD service of the metropolitan region of Belo Horizonte/MG. So, it was possible to identify feasibility, weaknesses and potential difficulties of application of the instruments, which allowed to make adjustments and to adapt them for the implementation of the phase of field research. The application of the instruments in a group similar to the target of the research allows the group of evaluators to

perceive how to approach the people to be investigated, increases the affinity with the questions, allows to check the pertinence and suitability of the same ones regarding the form of elaboration and vocabulary. It also allows to estimate the time of application of the instruments.

After the sample calculation, a total of 385 RCPD users were defined, at the significance level of 5%, divided by the 13 expanded health regions according to Table 1.

**Table 1.** Sample size by expanded health region and by service modality

Expanded Health Region	N by service modality of the Expanded Health Regions							N total*
	SRV	SERDI	SASA	SRF	SASPO	CER	SRF/SASPO	
Center	5	59	21	10	11	6	5	117
South Center	1	9	0	2	2	0	2	16
Jequitinhonha	0	3	0	0	0	3	0	6
East	0	14	3	3	3	3	2	28
South East	0	8	2	0	1	2	2	15
Northeast	0	7	1	1	2	0	0	11
Northwest	0	8	0	0	0	3	2	13
North	0	4	3	0	0	8	4	19
West	0	12	2	1	10	2	0	27
Southeast	0	22	1	2	6	1	0	32
South	0	47	1	3	6	1	0	58
Northern Triangle	0	16	1	2	6	2	0	27
Southern Triangle	2	10	1	0	0	1	2	16
Total	8	219	36	24	47	32	19	385

Legend: \*= Total N considering the margin of error of 5%; CER = Specialized Rehabilitation Center; SASA = Hearing Care Service; SASPO = Oustomized Patient Care; SERDI = Specialized Rehabilitation Service for Intellectual Disability; SRF = Physical Rehabilitation Service; SRV = Visual Rehabilitation Service.

### *Instrumentation and follow-up of the project*

The step of instrumentation and follow-up of the project was divided in several phases, namely:

- a) Presentation of the theme, in the first meetings, by two members with expertise in RCPD, acting in the SES/MG, with focus on its objectives, complexity and structuring within the State of Minas Gerais. Subsequently, the study of articles related to the subject began as a way to define the theoretical reference to be adopted in the research;
- b) Formatting of the research for submission and approval by the Research Ethics Committee of

the Federal University of Minas Gerais (COEP/UFMG).

- c) Selection of fellows through interview and analysis of the resume. The following professionals were selected: a speech therapist, MSc. in related areas (Fellowship of Science and Technology Management Level II) to assist in the project management and activities of the fellows; a speech therapist, MSc. in related areas (Fellowship of Technical Support Level I); three speech therapists (Fellowship of Science and Technology Management Level III) and two students of speech therapy (Fellowship of Undergraduate Research).

d) Meetings were held to present the theme for the fellows and, later, seminars to present the elaborated instruments, mainly aiming at the standardization in its application in order to avoid possible biases in the research. Periodic meetings were held for the continuous follow-up of the research.

The objectives foreseen for the realization of the project, as well as its current step are described in chart 2.

After these stages, the next ones contemplated the field research, already in phase of realization, as well as the production of scientific works with the obtained results.

**Chart 2.** Expected objectives and step of achievement

Specific purposes	Activity	Stage
1. Map the Disabled People Care Network in Minas Gerais, identifying the points of care that comprise it, its coverage area and the types of services offered by each of these points.	Analysis of the secondary data provided by the State Secretariat of Minas Gerais by the research team.	Concluded.
2. Describe the spatial distribution of the Disabled People Care Network in the State of Minas Gerais.	Analysis of the secondary data provided by the State Secretariat of Minas Gerais by the research team.	Concluded.
3. Analyze the perception of the professionals that compose the Disabled People Care Network about the implantation of the same in the area covered by the service in which they actuate in the selected municipalities.	Application of a semi-structured questionnaire elaborated by the researchers.	In phase of data collection. The data compilation and analysis are missing.
4. Analyze the physical structure and the human resources of the Disabled People Care Network in the selected municipalities.	Application of a semi-structured questionnaire elaborated by the researchers.	In phase of data collection. The data compilation and analysis are missing.
5. Identify the users of the Disabled People Care Network in the selected municipalities.	Application of a semi-structured questionnaire elaborated by the researchers.	In phase of data collection. The data compilation and analysis are missing.
6. Analyze the users of the Disabled People Care Network in the selected municipalities.	Application of a semi-structured questionnaire elaborated by the researchers.	In phase of data collection. The data compilation and analysis are missing.
7. Verify the association between the perception of professionals and users and the structure of the services of the Disabled People Care Network in the selected municipalities in relation to individual, demographic, socioeconomic characteristics and the Index of Social Responsibility of the State of Minas Gerais.	Hiring of statistical advice for data analysis. Previously, the data collected will be inserted in a database and checked for further analysis. A descriptive analysis of the frequency distribution of all categorical variables and analysis of the measures of central tendency and of dispersion of the continuous variables will be made. For association analysis, chi-square and Fisher's exact tests will be applied, considering those with a value of $p < 0.05$ as statistically significant.	In phase of data collection. The data compilation and analysis are missing.
8. Analyze the path between the residence and the services that compose the Disabled People Care Network in the selected municipalities.	Data obtained through the semi-structured questionnaire applied. The analysis will be performed by the hiring of statistical advice.	In phase of data collection. The data compilation and analysis are missing.

## Discussion

In the field of collective health, the decentralization and regionalization of actions and guidelines of the Unified Health System (SUS) are essential for the implementation and consolidation of the health system as a response to the health needs of the population. By sharing the competencies and responsibilities among the federated entities, the organization of actions and services to promote the integrality and equity of the assistance rendered is allowed, and also the waste of resources employed is avoided<sup>17-19</sup>. However, this process is complex and faces several difficulties, among them, the commitment of the municipalities to provide care to the population according to their actual capacity, in a responsive and integrated way in all levels of care<sup>18</sup>. The understanding of the regionalization, not only as a way to rationalize the offer of services, can broaden this debate by considering, in this process, other aspects of the territory and its economic, political, social and cultural dynamics. In this sense, the regionalization can be seen as a possibility of local response not limited to the health sector<sup>19</sup>. Therefore, in addition to the initial mapping of the Disabled People Care Network, which presents the territory and health regions as its organization, it is necessary to better understand the local dynamics and possible combinations of the set of services with other arrangements external to the health sector.

Considering the importance of the health evaluation for the formulation and implementation of public policies and the methodology of this project, which proposes the analysis of three elements (structure, process and result)<sup>20</sup>, the instruments of the present research were elaborated by the researchers in order to address and understand the local organization of the services, based on the evaluation of the structure, satisfaction of users and professionals and follow-up of the RCPD. It is emphasized that in order to establish an evaluative process, it is essential that its construction presents logical, coherent and rational bases in order to give reliability to the obtained data<sup>21</sup>. It should also be noted that the choice of the normative evaluation approach is due to the scope of the Network while-subject of this study, to the incipient data available in the literature and to the need to produce useful information to the manager of the RCPD. Although the normative assessment does not present elements

of a participatory evaluation - denominated fourth generation, it is pertinent as presents strategic and formative purpose<sup>22,23</sup>. In that sense, this research will be able to support the planning and provide information to improve the ongoing intervention.

Regarding the collection instruments elaborated by the research group, the step of pilot study, prior to the collection phase, was essential to test, evaluate, revise and improve the procedures proposed in the methods. This step allowed the identification of weaknesses of the instrument and its application, which could be reviewed before the concrete implementation of the research<sup>24</sup>, and also allowed to estimate the time required in each application. This revision process of the instruments was carried out by the whole team, allowing their construction and reconstruction from multiple perspectives, and also to minimize specific doubts of the application, and to resume and revise specific aspects of the methodology and stages of the study<sup>25</sup>. In this context, it was possible to guarantee a minimum standardization expected in the data collection, already involving the evaluators in the process of qualification for the use of the instrument.

The elaboration of the sample calculation is justified since it is desired that the study be representative of the population, aiming, therefore, that the results found allow inferences on the whole network. The parameters used in the calculation contributed to reduce the probability of random differences between the groups<sup>26</sup>.

In the instrumentation and follow-up stages of the project, several phases were carried out. Initially, the focus was on the approach and discussion of the chosen theme through periodic meetings and group study. Most of the scientific research, regardless of the knowledge area, had strict protocols as criteria, defined according to the design of the study and the standard of the researcher<sup>27</sup>. However, it is essential to consider the diversity of the knowledge within the group, whether through discussion meetings, study groups, round-table discussions, workshops or other means. Thus, individual experiences and practices are presented as a way to aggregate knowledge to the group/study, since no researcher is the sole holder of knowledge<sup>27</sup>.

The definition of the theoretical reference to be adopted, also carried out in the initial phases, helped in the selection of procedures and methodological aspects to be used, since it allowed



to approach with the theme of the study and to define concepts. However, it should be noted that, although some definitions were made in the initial stages, changes were made during the execution of the project, according to group discussions and feasibility aspects especially observed in the phase of data collection. Therefore, it is understood that some degree of flexibility is required regarding planning in all stages of the project, since it makes possible to reformulate and adapt the design of its study, bringing it closer to its objective<sup>28</sup>. This practice even allows new methodological models/paths to be developed and shared with other peers.

After the approval of the project by the Research Ethics Committee, fellows were selected to compose the research team. First, the fellow of the Science and Technology Management (Level II) was selected to provide technical and auxiliary support in the management of the project activities and field research, and later the other fellows, with functions of technical support and field research, were also selected.

Regarding the selection of fellows, it was observed that the inclusion of new members in the research group through clear criteria, as well as the definition of the function of each one, favors the establishment of well-defined guidelines to the project, respecting the differences, but without losing the characteristic of a safe and objective leadership<sup>29</sup>. Another important dimension is the training of new researchers through the experience of all stages of a study and the exchange of experiences and knowledge with advisors, researchers and other members. It is also worth noting the relevance of the insertion of fellows of undergraduate research into research groups, which gives the graduates not only the experience in research practices<sup>30</sup>, but also the formation of their critical-reflexive sense.

In the stage of instrumentation of the fellows, the main objective was the insertion of the new members in the subject of the study and also the standardization of the process of application of the collection instruments. There were group discussions on the theme, seminars to explain the developed and adopted instruments and seminars to standardize the application of the instruments<sup>25</sup>.

At the time of drafting, the present research was in the final phase of field collection, but has already systematized preliminary results for presentation in congresses and scientific events. This moment is also very important for the team, which

can review the established processes and qualify the fellows for the elaboration of abstracts and articles, presentation of papers, reflection on data analysis.

## Conclusion

The selection of the methodological path used to design this study allowed the researchers to systematize all the process of elaboration and development of a research project. It is believed that the study presents contributions to the scientific community, as it reports the steps drawn by a team to elaborate its research project and the methodological aspects used. The registration of this path is relevant in order to enable new studies to replicate this process and consequently allow the comparison with results obtained in other scenarios. It is hoped that the results obtained in the next stages can contribute to the critical analysis of the implementation of the RCPD in Minas Gerais and its impact on the quality of life of the user, aiming at the progress of the construction of integral assistance and the adequacy of current policies. In addition, it can provide subsidies to allow improvement measures to be adopted in the management of RCPD statewide, in order to promote the real integration between managers, health professionals and users.

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