



Reports from the Health Research Institute Partnership

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IIS Researchers' Careers

GT1. *Institute Partnership*. 2021.

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Executive Summary

The aim of this document is to set out the needs, considerations, obstacles, etc. of IIS in order to enable their research staff to develop a professional career that strengthens R&D&I in the National Health System. It is necessary to distinguish between two career paths depending on the researcher's employer: a professional research career for researchers employed by foundations/institutes and the statutory career path, which is aimed at health care professionals working in NHS health centres. All IIS and autonomous communities need to define a coherent and attractive career path for NHS research staff for both itineraries (employed and statutory), articulated in successive stages with increasing responsibility and reward between these stages, leading to job stability. To achieve this, it is necessary to overcome some limiting barriers: exemption from the replacement rate for stabilising research staff in the IIS/Foundations, creation of a category of clinical research staff throughout the NHS, and standardisation of scales in public examinations and job exchanges for statutory staff. All this will lead to a strengthening of the IIS in its most fundamental axis: the human resources dedicated to research.

Introduction

More and more countries are including health research programmes in their political agendas, with the aim of promoting research and integrating it into the backbone of the formal structure responsible for health care. In this way, the motivation for research, which has historically been lacking in most health professionals, is promoted as it is incorporated as a key and fundamental element in the development and training of health professionals throughout their careers.

Unfortunately, the recognition, promotion and opportunities for professional development in this field are not as adequate and uniform as they should be. This means that the grey mass that in many cases makes scientific progress possible is grouped and tied to certain countries, creating major inequalities at the global level and encouraging the exodus of professionals from countries where there are no incentives for research in search of better job opportunities that allow them to develop their research work.

The COVID-19 pandemic has shown that human society is still vulnerable to unknown health problems and that there is still a need to increase health research capacity in order to find appropriate diagnostic, preventive and therapeutic means.

In this sense, specific training in this field is a particularly relevant addition for any health professional, given that the current map of the most prevalent groups of diseases, both in terms of burden and lethality, such as cardiovascular diseases, oncological diseases and mental health, pin their hopes on research to make progress in improving management and reducing mortality.

Therefore, the health system needs professionals who, in addition to a professional career as a specialist, have the opportunity and the need to pursue a research career in their chosen field in order to provide answers to all the medical, scientific, technological, etc. challenges of our present and immediate future.

Accredited IIS must have a register of staff involved in their activities, indicating the organisational dependence of researchers on teaching hospitals and public and/or private R&D&I centres and their functional dependence on the IIS. This register will also include the IIS management unit's own staff (research, management and administration staff).

This means that the staff of the IIS may have different contractual modalities and categories: research staff (employed or statutory), technical support staff, R&D&I management staff, etc. As a result, the development of their professional careers in the IIS environment presents different itineraries. In this discussion paper, we focus on the design and development of the professional careers of research staff who are either contracted by the managing body of the IIS or attached as statutory staff to the health centres that make up their respective IIS.

During the 1st Forum of accredited IIS organised by the ISCIII in 2019, the initiative to form working groups, led by some institutes, was proposed in order to respond to and homogenise aspects and problems for all IIS currently accredited by the ISCIII. In 2020, the ISCIII carried out the creation of five working groups on the aspects to be improved, standardised, solved, etc. common to all accredited IIS. Due to the Covid-19 pandemic, this initiative was halted and the coordination of these groups was resumed in 2021, including the working group on the research career of IIS.

The following IIS participated in this working group: IGTP, BIODONOSTIA, IMIBIC, IISGM, INCLIVA, IR-VHIR, IBASAL, IMIM, IDIPAZ, Ibs.GRANADA, IdISSC, IdISBa.

The aim of this group is to draw up a document setting out the needs, considerations, obstacles, etc. of the IIS in order to enable their research staff to develop a professional career that strengthens R&D&I in the National Health System, either through the health services or in foundations/health research institutes, promoting mobility and international cooperation, carrying out research of excellence and promoting the transfer of knowledge to the productive sector and society.

Theoretical Framework

With regard to the Health Research Institutes, the partnership of centres of different types (clinical, academic, scientific, etc.) that make up the IIS leads to a dispersion of the research careers that can be pursued by all the members of these centres.

At present, most of the research staff recruited by the IIS management body are subject to the general legal regime of the instrumental public sector of the Autonomous Communities, which does not take into account the specificities inherent to the research task and does not provide for the existence of a research career understood as an ordered set of promotion opportunities and expectations of professional progress in accordance with the principles of equality, merit and capacity.

This lack of definition of a research career and of a specific legal regime for employed researchers leads to major shortcomings in terms of recruitment, selection systems, incentives, monitoring and evaluation of research work. This leads to the precariousness of researcher jobs and the loss of the ability to attract research talent, which contributes to the loss of competitiveness of the national research, development and innovation system.

On the other hand, the National Health System (NHS) is not designed for the professional development of a research career, although Article 85 of Law 14/2007 of 3 July, on Biomedical Research, already provides for the promotion of research activities in the centres of the National Health System:

“1. The Public Administrations, in the framework of their human resources planning, shall promote the integration into the health services of categories of research staff under the statutory regime.

In the case of centres that are linked, subsidised or covered by the new forms of management of the National Health System, established by Law 15/1997, of 25 April, the admission of research staff shall be carried out in accordance with the corresponding legal regime.

In both cases, this incorporation will be carried out through the selection procedures established by law, which in all cases will be in accordance with the guidelines for access to public employment established in article 55 of Law 7/2007, of 12 April.

2. The Centres of the National Health System, including those referred to in the second paragraph of the previous section, if they are beneficiaries of public aid or subsidies that include among their purposes the contracting of research staff, may contract research staff in accordance with the contractual modalities established in Articles 21 and 22 of Law 14/2011, of 1 June, on Science, Technology and Innovation, and in accordance with the provisions of the aforementioned Law.

In the case of the contract for access to the Spanish Science, Technology and Innovation System referred to in the aforementioned Article 22, the Centres may employ doctors or specialists who have completed specialised training in the field of health. The evaluation referred to in the aforementioned article shall be carried out in the manner established by regulation.

3. Research activities, as well as national and international mobility for research purposes, shall be taken into account in the scales of merit for access, promotion and, where appropriate, development and career advancement of health and/or research professionals in the National Health System.

4. Within the framework of the respective health services, measures shall be taken to promote the health and research activities of their professionals, their participation in international research programmes and their compatibility with the exercise of activities in other research institutions, subject to the provisions of Law 53/1984 of 26 December 1984 and, where applicable, the Autonomous Community laws on incompatibilities.”

Unfortunately, very few Autonomous Communities currently have the category of clinical research staff in their health services, within their professional categories, and the recognition of the research activity undertaken by professionals in the assessment of merit for access, promotion and development of a professional career in the NHS. As a result, it is difficult to make a research career both possible and attractive for health professionals in the current NHS.

Furthermore, in the working environment of IIS there are also other professional profiles that are not identified in the research career, but which are necessary for the proper functioning and management of the IIS and, in some cases, mandatory in order to accredit an IIS according to RD 279/2016.

In this sense, we are talking about technical research support staff who carry out functions and activities in laboratories, research groups or scientific-technical platforms.

Other essential and necessary staff for the correct and guaranteed management of R&D&I are the management staff in charge of coordinating or supervising those tasks that are complementary to the research activity and which, in some cases, require specialisation to carry out their management work within the IIS (e.g. bioinformaticians, lawyers specialised in data protection, etc.).

However, the professional careers of these other profiles will be addressed by the IIS in future working groups.

This working group has considered how a research career should be designed in the institutions that do not currently have a research career, although they conduct health research, such as health centres and health research foundations.

Therefore, this document does not deal with the evaluation of research careers in other centres such as the CSIC, universities, etc.

Methodology

In July 2020, and as a consequence of the global pandemic of COVID-19, the Ministry of Science and Innovation published a shock plan for science and innovation based on 3 main axes.

Axis 1 of this plan is dedicated to health research and innovation. Specifically, goal 4 aims to reform Law 14/2007 of 3 July on Biomedical Research. The objectives of this goal are to update the law and its regulatory development in order to:

- 1) Develop a stable research career in the centres of the National Health System.
- 2) Develop the Sectoral Initiative for Health Research.

One of the actions proposed was the development of Article 85 on research careers in NHS centres of the Law on Biomedical Research, which had not been developed after more than a decade. The following changes are proposed:

- To bring hospital research staff into line with the categories of other public centres in the country: universities, PRBs and other centres.
- To allow for their professional advancement through the application of a tenure track path leading to professional stabilisation, following an appropriate assessment of research activity.
- To provide a legal framework for the development of the necessary regional regulations to guarantee the homogeneity of criteria throughout the National Health System.
- To expressly include in the Law on Biomedical Research the regulation on the mobility of research staff contained in the Law on Science. This will allow NHS staff to take temporary leave to join other public or private bodies in the Spanish Science, Technology and Innovation system or other international or foreign bodies, as well as to provide services in trading companies.

Researchers in NHS health centres are employed to carry on a health care activity, but some professionals also devote time to research activities, mainly clinical, although there may be situations where their research is basic translational. This research activity is carried out on a part-time basis and in most cases is not recognised as part of the duties of their employment contract. This type of research staff is attached to the IIS as they are employed by the regional health services and are therefore statutory staff. For this type of professional, a statutory research career should be defined, taking into account the specificities of access and stabilisation of health service staff.

Similarly, the IIS include research staff who, in most cases, carry out basic-translational research on an exclusive basis. They are usually recruited by the Foundations/Institutes and are therefore considered to be employees. For this reason, a research career path should be defined for this type of staff, taking into account the needs of these institutions for the implementation of a research career.

However, the research staff that form part of the IIS also come from other institutions such as universities, PRBs, CSIC, etc. In this document, we have focused on trying to identify the obstacles and limitations that the institutions to which these researchers belong have to be able to develop a research career.

Bearing in mind that the nature of these researchers' contracts is different and in order to take into account the specificities of each contracting institution, we will distinguish between two career paths depending on the researcher's contracting institution.

Development and Results

What is meant by career of research staff?

Law 14/2011, of 1 June, on Science, Technology and Innovation, expresses the need to define a predictable, merit-based and socially recognised scientific career. Therefore, a research career should be understood as an ordered set of promotion opportunities and expectations of professional progress in accordance with the principles of equality, merit and capacity.

Research career for non-established public employees

The contractual research career path of researchers contracted by Foundations/Institutes, who are usually exclusively dedicated to research, would have four successive stages, with corresponding evaluation and co-funding programmes: first, there would be the pre-doctoral stage, lasting a maximum of 4 to 6 years, with the aim of completing the doctoral thesis. This would be followed by the "junior" postdoctoral phase, lasting a maximum of 4 to 6 years, during which researchers would have to spend time in other centres, mainly international ones. This is followed by the "senior" postdoctoral phase, with contracts for 5 years to incorporate research staff, and a final evaluation of the employees' research activities. Finally, there is the stabilisation phase for researchers who have already achieved scientific independence and have formed their own research groups.



Figure 1. Outline of the Contractual Research Career Path in the IIS

Currently, a researcher following the contractual path is stabilised at the age of 40 or older, after having undergone an evaluation of his/her research activity throughout his/her career.

What would be the stabilisation process for non-established researchers in an IIS?

Currently, research staff with translational research activity are recruited by the management body of the IIS under employment contracts. These staff are subject to the general legal regime of the instrumental public sector of the Autonomous Communities and the access route to stabilisation is usually through a Public Job Posting (OPE).

Obstacles

- Most of the Autonomous Communities do not have a statute for contractual research staff that defines the research career and their specific legal regime.
- Moreover, as IIS are young institutions, many of them do not have the staff turnover rate to be able to create and fill positions in order to publish an OPE.
- The OPE processes have to pass through the filters of the regional General Directorates of Budgets and Public Function, which do not understand or have insufficient knowledge of what a research career consists of. Moreover, due to these filters, the bureaucratic process of publishing an OPE takes a long time and does not leave much time to find candidates who want to apply to the calls of the funding bodies.

Proposals for a contractual research career model

- Researchers who have passed through the above stages should not be required to take one or more entrance examinations, as is the case in the administrative and technical bodies of the public administration, so that they have direct access to stabilisation after a positive assessment process in stage 3.
- Exemption from the replacement rate for the stabilisation of research staff in the IIS.
- Obligation for the Health Service to transfer the annual replacement rate to the Foundations/IIS.

What measures are being taken in the ISCIII-accredited IIS or by the Autonomous Communities to stabilise non-established researchers?

In some Autonomous Communities, there are calls for "stable" incorporation contracts that can be applied for after the end of the Miguel Servet contract. In Catalonia, contracts at research centres are offered on a competitive basis through ICREA and in the Basque Country through Ikerbaske. In these Autonomous Communities, the recruitment and stabilisation of research staff is facilitated by the relevant regional regulations, which allow the creation of instrumental bodies of a private nature, but with public funding. In Andalusia, after the Miguel Servet contract, the Nicolás Monardes contract provides continuity to the research path, with a competitive selection process for 4-year renewable contracts.

In the Community of Madrid, the collective agreement of the Group of Biomedical Research Foundation (FIB) Companies of the Health Institutions of the Madrid Health Service (SERMAS) was published on 22 December 2020. It establishes 3 functional areas (research, scientific-technical and administrative and management) and 10 professional categories, and is valid for 3 years. For the first time, it has made it possible to categorise all staff in the different FIBs of the Community in the same way. The agreement itself includes the category of Associate and Tenured Researchers, in line with the aforementioned path, and the creation of a Joint Commission whose functions include defining a professional development for the Community of Madrid. No conclusions have yet been reached.

With regard to staff stabilisation, the Community of Madrid has exceptionally offered public positions in SERMAS for the stabilisation of staff in the Foundations (year 2020) and has made use of what was published in the BOE in Law 3/2017, of 27 June, on the General State Budget for 2017, which authorises an additional rate for the stabilisation of temporary employment. Since then, it has been possible to stabilise staff on an ad hoc basis.

In the Balearic Islands, the Statute of Contractual Researchers at the service of the Health Research Institutes of the Balearic Islands was approved in 2019 (Decree 17/2019). This statute aims to establish the legal regime of the contractual research staff of the IIS in the Balearic Islands integrated in the instrumental

public sector of the Autonomous Community, as well as to define the structure of the categories of researchers and their corresponding research careers, the selection and recruitment process, and the assessment regime, among others.

Furthermore, in Catalonia, the CERCA (Research Centres of Catalonia) institution, created in 2011, has the mission of ensuring the appropriate development of the Catalan research centre system; promoting and maximising synergies, coordinating centres and strategic cooperation; improving the positioning, visibility and impact of the research carried out; and facilitating dialogue with the different public and private actors.

Some of the centres considered as ISCIII-accredited IIS belong to this Institution and therefore benefit from the management autonomy recognised for the first time for CERCA centres in Law 7/2011, of 27 July, on fiscal and financial measures. In particular, the CERCA institution allows "flexible and efficient management, based on self-demand and quality, measurable by international standards" and "CERCA centres enjoy full autonomy in the development of their foundational or statutory activities".

The autonomy regime includes, in any case, the human resources policy, which includes the selection, the recruitment, the remuneration system, and the determination of the compatibility of the staff, as well as the conditions in which they have to carry out their activities.

Research career for statutory employees

The Statutory Path is aimed at health care professionals working in NHS health centres. In this case, we would distinguish 3 stages, which normally start after the completion of a specialist medical training (from 3 to 5 years). Its objective is to train health professionals who have completed the period of specialist medical training regulated for medical, pharmaceutical, chemical, biologist, clinical psychologist, nursing and hospital radiophysics staff, through the development of a training plan in basic biomedical, clinical or public health research, in centres with accredited research capacity and under the direction and supervision of a research group.

The aim is to develop the research skills of future NHS health professionals and to promote the multidisciplinary dimension of research activity and its transfer to the NHS. This stage takes the form of a two-to-four-year contract, after which the professional joins the NHS as an Area Specialist, as defined by regulations, to carry out their healthcare, teaching and research activities. It is also a period of research training during which a doctorate can be obtained. The next stage would be the "junior" postdoctoral stage, with 3-year contracts and the need for the researcher to spend time in other centres, preferably internationally. Then we would have the "senior" postdoctoral stage, which would be channelled through a 4-year contract for incorporation into the NHS. Currently, there is no general stabilisation process in all the Autonomous Communities for these professionals combining their healthcare, research and teaching activities.

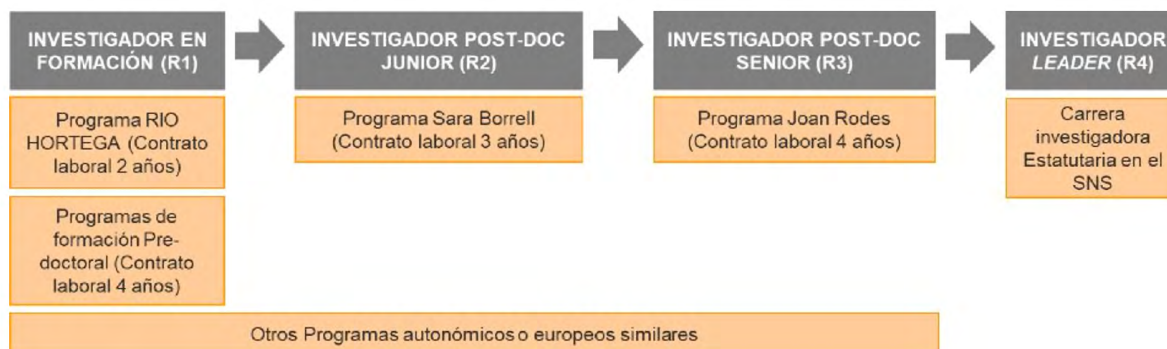


Figure 2. Outline of the Statutory Research Career Path in the IIS

On the other hand, the Research Intensification Programme has been designed with the aim of freeing health professionals from health care activities for a period of time, facilitating the involvement of NHS health professionals as Project Main Researcher by partially releasing them from their health care responsibilities. However, these programmes are usually of a fixed duration, not exceeding one year, and although they help to increase the research activity of health professionals, they do not address the need for more sustained commitment to their research projects over time in order to be competitive in their research areas.

What would be the stabilisation process for statutory researchers in an IIS?

Clinical research staff assigned to an IIS are usually contracted by the NHS health service as medical specialists to carry out healthcare work. Their stabilisation is through the General Public Job Posting published in each Autonomous Community. Therefore, they have the possibility of being stabilised as specialist health professionals, but not as research staff, as this category is not generally included in the national map of the NHS.

Obstacles

- Lack of the category of clinical research staff in the NHS. As the category of clinical research staff does not exist in most of the Autonomous Communities, the OPEs published do not consider the figure of a health professional who, in addition to working part of the day as a health professional, devotes another part of the working hours to research activities.
- In the assessment of merit for the regional health service job banks and competitive examinations, the time spent on statutory contracts is not usually given the same weighting as the time spent as a specialist (general practitioner). At present, only 4 Autonomous Communities have achieved this. However, there is a limiting factor in the form of the Autonomous Communities' recruitment committees, which in many cases oppose this measure.

Proposals for a statutory research career model

- Creation of a category of clinical research staff throughout the NHS, accompanied by an annual OPE.
- Harmonisation of the scales used in the OPEs for statutory staff, so that the time worked as medical specialists in the Río Hortega and Juan Rodés modalities, financed by the Institute of Health Carlos III, counts the same as that for medical specialists in other health positions. And to extend it to other competitive programmes financed by the regional administrations and aimed at medical research specialists.
- Definition of an assessment and progression of the statutory research career according to research activity and scientific production (publications, research projects and funding obtained in competitive or non-competitive competition, etc.), so that those who accumulate more research recognition can receive salary supplements or even reduce their healthcare workload.

What measures are being taken in the ISCIII-accredited IIS or by the Autonomous Communities?

Only some Autonomous Communities, such as Aragón, Cantabria, Valencia and, more recently, Castilla y León, have managed to give the Río Hortega and Juan Rodés contracts the same weighting as the work experience of a general specialist practitioner period.

In the Balearic Islands, steps have been taken to create the category of clinical researcher in the Balearic Islands Health Service. Since the approval in 2019 of Decree 45/2019, of 24 May, which creates, modifies

and suppresses different categories of statutory staff within the scope of the Balearic Islands Health Service, modifications have been made during 2021, which have given the possibility of including this new category. The implementation process is currently in the negotiation and discussion phase with the health trade unions.

Conclusions and Suggestions

All IIS and Autonomous Communities need to define a coherent and attractive career path for NHS research staff for both itineraries (contractual and statutory), articulated in successive stages with increasing responsibility and reward between these stages, leading to job stability, avoiding precarious working conditions for research staff and promoting equal opportunities to foster a competitive health research system to be a benchmark at international level.

All this will lead to a strengthening of the IIS in its most fundamental axis: the human resources dedicated to research.

In order to achieve this objective, it will be necessary to overcome some of the limiting obstacles already mentioned, such as:

- Consideration of exemption from the replacement rate for the stabilisation of research staff in the IIS/ Foundations.
- Alternatively, obligation for the Health Service to transfer the annual replacement rate to the IIS/ Foundations.
- Creation of a category of clinical research staff throughout the NHS to combine healthcare, research and teaching activities.
- Harmonisation of the scales used in the OPEs job banks for statutory staff, so that the time worked as medical specialists in the Rio Hortega and Juan Rodés (and related) modalities counts the same as that for medical specialists in other health positions.

On the other hand, during the search for information for the drafting of this document, no recent publications were found that collect information on the activity and results of the R&D&I of the IIS as a whole. Nor how this activity of the IIS is positioned in relation to the R&D&I generated in Spain and Europe. For this reason, the working group believes that it would be very useful to make an effort in this direction and to promote this type of publication, which demonstrates the importance of the biomedical research carried out by the IIS. This information will help to make visible and support the need for a research career in IIS.

Strategies to Facilitate the Development of Open Access (OA) in IIS: the Health Institutional Repository of ISCIII

GT3. *Institute Partnership*. 2021.

Coordination: IBIMA

Manager: Dr. Francisco Tinahones. Scientific Director IIS IBIMA-Bionand Platform.

Executive Summary

This report is the result of the “Open Access Working Group” of the Health Research Institutes Forum 2021 of the Institute of Health Carlos III (ISCIII), where the group was created to facilitate the development of Open Access in Health Research Institutes (IIS). This document defines conclusions and recommendations for the effective implementation of Open Access, as a result of the analysis and diagnosis of the situation of the IIS that make up the working group. The document also includes the theoretical and normative framework at national and international level.

Introduction

The aim of this document is to collect the joint reflections of the accredited Health Research Institutes (IIS) on “Strategies to facilitate the development of Open Access (OA) in their institutions” in order to:

- Address the needs of IIS in the dynamic R&D&I environment.
- Align the scientific policies of IIS with the strategic lines of the European framework.
- Encourage cooperation between IIS creating synergies that increase their competitiveness.
- Promote the participation of the IIS in the definition of the action lines of the ISCIII.

Theoretical Framework

Preliminary definitions.

Intellectual Property and Copyright:

Copyright protects the author of a work. Moral and economic rights are recognised. Moral rights are inherent to the status of author and cannot be waived; economic or exploitation rights can be transferred. The Law on Intellectual Property (BOE 97, 12 April 1996) recognises the following moral rights of authors: “The author has the following unwaivable and inalienable rights:

1. To decide whether and in what form his work shall be disclosed.
2. To determine whether such dissemination shall be made under his name, under a pseudonym or pen name, or anonymously.
3. To demand recognition of their status as the author of the work.
4. To demand respect for the integrity of the work and prevent any distortion, modification, alteration or attack against it that would be prejudicial to his legitimate interests or detrimental to his reputation.

5. To modify the work while respecting the rights acquired by third parties and the requirements for the protection of goods of cultural interest.

6. To withdraw the work from the market due to a change in his intellectual or moral convictions, subject to compensation to the holders of the exploitation rights.

If the author subsequently decides to resume the exploitation of his work, he must preferentially offer the corresponding rights to the previous rightsholder and on terms reasonably similar to the original ones.

7. To access to the only or rare copy of the work when it is in the possession of another person, in order to exercise the right of dissemination or any other right to which the author is entitled.

This right shall not require the work to be moved, and access to the work shall be granted in the place and in the manner that causes the least inconvenience to the owner, who shall be compensated, where appropriate, for any damage and prejudice caused.”

The economic or exploitation rights are the rights of reproduction, distribution, public communication and transformation. These can be transferred by contract for a certain period of time. This is where scientific societies and publishers come in, as they make authors sign a contract that obliges them to transfer the exploitation rights of their works. In Spain, the economic rights last for the life of the author and seventy years after his or her death. When this period expired, the work enters the public domain and can be used by anyone, generally free of charge.

The transfer of exploitation rights to third parties can be done in two ways: cession and license. In the case of cession, the ownership of the rights is transferred. In the case of license, the right to use or exploit the object protected by the intellectual property is granted under certain conditions, which may include financial considerations.

One of the critical aspects of academic publishing is that journals often require authors to transfer the exploitation rights of published works. In order to cover and preserve the copyright regime, Creative Commons licences were created in the late 1990s. The aim of these licences is to provide a standardised model that protects the intellectual property of authors and allows it to be re-used under certain conditions.

Open Access:

UNESCO defines Open Access as the free access to information and unrestricted use of electronic resources for everyone. Any kind of digital content can be OA, from texts and data to software, audio, video, and multi-media. While most of the available digital content is related to text only, a growing number of resources are integrating text with images, data, and executable code. Open Access can also apply to non-scholarly content, like music, movies, and novels.

According to Peter Suber (2012), a philosopher and legal scholar specialising in Open Access who has been at the forefront of this movement since its beginnings, Open access (OA) literature is digital, online, free of charge, and free of most copyright and licensing restrictions. In order to disseminate a work in open access, three conditions must be met:

- The work must be freely and universally available on the Internet or any other medium, at no cost to the reader.
- The author must grant all potential users the right to use, copy and distribute the work for an unlimited period of time, on the sole condition that authorship is acknowledged.

- The full version of the content must be deposited in electronic form in an Open Access repository that is internationally recognised as such and committed to Open Access.

On the other hand, as Remedios Melero points out in her article *Significado del acceso abierto (open access) a las publicaciones científicas: definición, recursos copyright e impacto*, it is important not to confuse free access with open access: free access is synonymous with free, whereas open access means being able to obtain an article without financial barriers and to disseminate it without any kind of restriction, claiming the authors' rights over their articles.

The benefits of Open Access for both institutions and authors focus on the visibility of research results and increased dissemination and use, which can lead to greater impact and open the way to new opportunities and sources of funding. According to Banerjee et al. (2015):

- It increases the visibility of researchers and institutions contributing to written scholarship.
- It facilitates the dissemination of scientific and scholarly publications to sectors that make relevant use of science.
- It develops digital platforms and databases whose content can be identified and imported online
- It enables the use of scientific and scholarly publications and their research inputs to make science work more efficiently
- It creates a portfolio of services that help consolidate scientific and scholarly publications and ensure the quality of their content
- It addresses the sustainability of scientific journals beyond the business model
- It facilitates collaboration and complementarity between flexible and interactive research communities

Within the framework of Open Access, there are different ways of making a publication available in OA.

The main and most traditional routes to Open Access are the "green" and the "golden", established on the Budapest Open Access Initiative.

Subsequently, other variants have emerged, such as the Bronze and the Diamond.

The green one, or self-archiving, is based on the practice of depositing previously published work in an open access repository. The repository may be institutional, thematic or general.

Open access to these articles may be subject to an embargo period set by editorial policy. Academic publishers often require authors to transfer copyright to them for a period of time, known as an embargo. This means that authors cannot publish the full text of their work until the embargo imposed by the publisher has expired. Each journal has its own copyright release policy. These outline the ability of authors to self-archive and the permissions for which versions of articles can be deposited in a repository. The editorial policies of academic journals can be consulted in the SHERPA/RoMEO database for international journals and in DULCINEA for Spanish journals.

Different versions can be deposited:

- Preprint: the version sent to the journal
- Postprint: the authors' final version, already peer-reviewed and approved for publication.
- Publisher's version: the version published in the journal

The golden route, or Open Access publication, consists of the publisher of a journal making the work immediately and permanently Open Access, under a licence in which the author retains the copyright of his or her work. Journals that allow it might be:

- Open access journals. Journals that usually require a payment for publication costs, called APCs (article processing charges).
- Hybrid journals, where access is by subscription, but where authors have the option of making the final version of their article immediately OA, subject to payment of APCs.

Publication costs are often quite high. These must be met by the authors themselves or by their institutions.

The bronze route refers to articles that are free to read on publishers' websites, but without an explicit open licence to allow distribution and re-use.

The diamond or platinum route refers to journals that publish openly and do not charge authors to publish or readers to read. These journals are usually funded by academic or government institutions or scientific societies.

Research data: It is not possible to apply a single definition across disciplines. According to the US National Institutes of Health or the OECD, research data are "factual records used as primary sources for scientific research, and that are commonly accepted in the scientific community as necessary to validate research findings".

The European Commission is currently encouraging beneficiaries of funding from the European Research Council (ERC), as well as most Horizon 2020 programmes, to establish data management plans and to deposit data resulting from EU-funded research in trusted repositories, when possible, in accordance with the FAIR (Findability, Accessibility, Interoperability, and Reusability) principles.

The CoreTrustSeal repository certification (<https://www.coretrustseal.org/>), an initiative of the Research Data Alliance (RDA), is widely accepted internationally and is being considered by the NIH as a trusted certification in its data science strategy.

Access to scientific results should be "as open as possible, as closed as necessary", balancing the openness of data with the protection of scientific information, commercialisation and intellectual property rights, privacy, security and data preservation and management issues.

Special consideration will be given to data generated in the course of healthcare and extracted from digital health records, taking into account the legal and ethical framework applicable to such data.

This obligation will be implemented from 2021 for all beneficiaries of grants from Horizon Europe programmes (2021-2027). To help meet these requirements, the European Commission is providing numerous services and resources through OpenAIRE, a technology and service infrastructure created in 2009 to support, accelerate and measure the correct implementation of European policies on Open Access to scientific publications and research data.

It is also required by the Institute of Health Carlos III since 2020 and is a requirement for the accreditation of Health Research Institutes.

Open Science:

Open Science represents a paradigm shift in the way research is conducted. It is a new model promoted by the European Commission, which proposes that it should be open, collaborative and conducted with and for society (Anglada and Abadal, 2018).

Background:

The first Open Access journals appeared in 1991, *Surfaces and Psychology*, by Jean Claude Guédon and Stevan Harnard (Melero, Abad 2008).

The advent of the Internet and the use of new technologies have been crucial to the development of Open Access, facilitating the availability of scientific and intellectual production to a wider public, in less time and at a lower cost. Indeed, the Public Library of Science (PLOS) published a letter on the Internet in 2001 asking publishers to allow articles to be published after a 6-month embargo (<https://www.plos.org/open-letter>). This action contributed significantly to the impact of the Open Access movement.

This was followed in 2002 by the Budapest Open Access Initiative (<http://www.budapestopenaccessinitiative.org/read>), a “statement of principle, strategy, and commitment”. According to the signatories, by “open access” [to peer-reviewed journal literature], we mean its free availability on the public internet, permitting any users to read, download, copy, distribute, print, search, or link to the full texts of these articles, crawl them for indexing, pass them as data to software, or use them for any other lawful purpose, without financial, legal, or technical barriers other than those inseparable from gaining access to the internet itself. The only constraint on reproduction and distribution, and the only role for copyright in this domain, should be to give authors control over the integrity of their work and the right to be properly acknowledged and cited.

It outlined two strategies for achieving open access to scholarly journal literature:

- Encourage self-archiving by providing scholars with the tools to deposit their refereed journal articles in open electronic archives. These archives should follow standards so that search engines can find them independently and so that they are interoperable.
- Encourage publication in Open-Access Journals that use copyright to ensure permanent open access to all the articles they publish, rather than restricting access to and use of materials. Publishers should seek new forms of funding based not on subscription fees but on contributions from agencies, public institutions and even authors themselves.

The Bethesda Statement was issued in 2003, <http://legacy.earlham.edu/~peters/fos/bethesda.htm>. This declaration defines an Open Access Publication as one that meets the following two conditions:

- The author(s) and copyright holder(s) grant(s) to all users a free, irrevocable, worldwide, perpetual right of access to, and a license to copy, use, distribute, transmit and display the work publicly and to make and distribute derivative works, in any digital medium for any responsible purpose, subject to proper attribution of authorship, as well as the right to make small numbers of printed copies for their personal use.
- A complete version of the work and all supplemental materials, including a copy of the permission as stated above, in a suitable standard electronic format is deposited immediately upon initial publication in at least one online repository that is supported by an academic institution, scholarly society, government agency, or other well-established organization that seeks to enable open access, unrestricted distribution, interoperability, and long-term archiving.

The Berlin Declaration was adopted on 22 October 2003 on the initiative of the Max Planck Society and has become a milestone in the Open Access movement: <https://openaccess.mpg.de/Berlin-Declaration>

This declaration is based on the fact that the Internet offers the chance to constitute a global and interactive representation of human knowledge, including cultural heritage and the guarantee of worldwide access. Its

interest is therefore to promote the Internet as a functional instrument for a global scientific knowledge base and human reflection and to specify measures which research policy makers, research institutions, funding agencies, libraries, archives and museums need to consider. So the Web has to be sustainable, interactive, and transparent, and the content and software tools must be openly accessible and compatible.

Open Access contributions include original scientific research results, raw data and metadata, source materials, digital representations of pictorial and graphical materials and scholarly multimedia materials.

Two conditions must be satisfied:

1. The author(s) and right holder(s) of such contributions grant(s) to all users a free, irrevocable, worldwide, right of access to, and a license to copy, use, distribute, transmit and display the work publicly and to make and distribute derivative works, in any digital medium for any responsible purpose, subject to proper attribution of authorship, as well as the right to make small numbers of printed copies for their personal use.
2. A complete version of the work and all supplemental materials, including a copy of the permission as stated above, in an appropriate standard electronic format is deposited in at least one online repository using suitable technical standards (Open Archive Definitions) that is supported and maintained by an academic institution, scholarly society, government agency, or other well-established organization that seeks to enable open access, unrestricted distribution, inter-operability, and long-term archiving.

Legal and strategic framework:

National Framework:

Law 14/2011, of 1 June, on Science, Technology and Innovation (<https://www.boe.es/buscar/doc.php?id=BOE-A-2011-9617>), includes the obligation of open access publication of publicly funded research. In particular, Article 37 is explicitly dedicated to Open Access dissemination:

Article 37. Open Access Dissemination

1. The public agents of the Spanish Science, Technology and Innovation System shall promote the development of their own or shared repositories for open access to the publications of their research staff, and shall establish systems that allow them to be linked to similar initiatives at national and international levels.
2. Research staff whose research activities are mainly financed from the General State Budget shall make publicly available, as soon as possible and no later than twelve months after the official date of publication, a digital version of the final version of the content accepted for publication in serial or periodical research publications.
3. The electronic version shall be made publicly available in recognised open access repositories in the field of knowledge in which the research was carried out, or in institutional open access repositories.
4. The public electronic version may be used by public administrations in their assessment processes.
5. The Ministry of Science and Innovation will facilitate centralised access to the repositories and their connection with similar national and international initiatives.
6. The above is without prejudice to the agreements under which the rights to publications may have been assigned or transferred to third parties and does not apply where the rights to the results of research, development and innovation activities are eligible for protection.

Subsequently, in 2014, the Spanish Foundation for Science and Technology (FECYT) (<http://www.fecyt.es/>) carried out a study, published as “Recomendaciones para la implementación del artículo 37 Difusión en Acceso Abierto de la Ley de Ciencia, la Tecnología y la Innovación” (http://recolecta.fecyt.es/sites/default/files/contenido/documentos/Implantacion_Art37_AccesoAbierto.pdf), with the participation of national experts and representatives of Spanish institutions. This document provides a practical guide that defines the main aspects of the Spanish Open Access policy and details a series of recommendations for the correct monitoring and assessment of the legal mandate.

In February 2012, Royal Decree 99/2011 (<http://www.boe.es/boe/dias/2011/02/10/pdfs/BOE-A-2011-2541.pdf>) came into force, which regulates official doctoral studies. Article 14 states that "once the doctoral thesis has been approved, the university shall ensure that it is archived in an open electronic format in an institutional repository and shall send a copy of this thesis and all the necessary supplementary information in electronic format to the Ministry of Education for the appropriate purposes".

We can also highlight the Declaration of REBIUN/CRUE (Spanish University Libraries Network/Crue Spanish Universities) in support of the open electronic access model, adopted in 2004 <http://blogs.ujaen.es/abiertobuja/wp-content/uploads/2017/01/DECLARACI%C3%93N-DE-REBIUN.pdf>.

Also, the Spanish Science, Technology and Innovation Strategy for 2021-2027 promotes excellent and open science, which is one of the fundamental pillars of Objective 4 (generation of knowledge and scientific leadership). It promotes an Open Science model that favours the generation of high-quality, high-impact knowledge that is transferred to society.

On the other hand, the Spanish State Plan for Scientific, Technical and Innovation Research for the period 2021-2023, within the State Sub-programme for Institutional Strengthening, includes two initiatives under "Open and Inclusive Science" for the implementation of Institutional Transformation Projects in Responsible Research and Innovation and through the co-financing of activities aimed at promoting the implementation of an open science model.

International (European) framework:

At the international level, the Horizon 2020 funding programme should be mentioned, which stipulates that researchers participating in EU-funded projects must publish scientific articles published as part of the project in a repository within a maximum period of six months. Article 29.2 of the 2020 Programme of the Annotated Model Grant Agreement http://ec.europa.eu/research/participants/data/ref/h2020/mga/gga/h2020-mga-gga-multi_en.pdf refers to scientific publications and 29.3 to research data:

29.2 Open access to scientific publications

Each beneficiary must ensure open access (free of charge, online access for any user) to all peer-reviewed scientific publications relating to its results. In particular, it must:

- a. As soon as possible and at the latest on publication, deposit a machine-readable electronic copy of the published version or final peer-reviewed manuscript accepted for publication in a repository for scientific publications. Moreover, the beneficiary must aim to deposit at the same time the research data needed to validate the results presented in the deposited scientific publications.
- b. Ensure open access to the deposited publication — via the repository — at the latest:
 - On publication, if an electronic version is available for free via the publisher, or

- Within six months of publication.
- c. Ensure open access — via the repository — to the bibliographic metadata that identify the deposited publication. The bibliographic metadata must be in a standard format and must include all of the following:
 - the terms ["European Union (EU)" and "Horizon 2020"] ["Euratom" and "Euratom research and training programme 2014-2018"].
 - The name of the action, acronym and grant number.
 - The publication date, and length of embargo period if applicable, and
 - A persistent identifier.

29.3 Open access to research data

It establishes that projects participating in the Research Data Pilot Scheme must develop a Data Management Plan (DMP).

Regarding the digital research data generated in the action ('data'), the beneficiaries must:

- (a) deposit in a research data repository and take measures to make it possible for third parties to access, mine, exploit, reproduce and disseminate — free of charge for any user — the following:
 - (i) the data, including associated metadata, needed to validate the results presented in scientific publications, as soon as possible;
 - (II) other data, including associated metadata, as specified and within the deadlines laid down in the "data management plan".

As an exception, the beneficiaries do not have to ensure open access to specific parts of their research data if the achievement of the action's main objective (as described in Annex 1) would be jeopardised by it. In this case, the data management plan must contain the reasons for not giving access.

Exceptions for reasons of security, privacy, protection of personal data or commercial/industrial exploitation may preclude open dissemination of project results.

The European Research Council (ERC) publishes guidelines for the implementation of Open Access for scientific publications and research data from ERC-funded projects:

http://ec.europa.eu/research/participants/data/ref/h2020/other/hi/oa-pilot/h2020-hi-erc-oa-guide_en.pdf

Similarly, the European Commission has also published guidelines on Open Access to scientific publications and research data in Horizon 2020 projects, with slightly different nuances depending on the ERC itself:

http://ec.europa.eu/research/participants/data/ref/h2020/grants_manual/hi/oa_pilot/h2020-hi-oa-pilot-guide_en.pdf

Currently, the Framework Programme for Research and Innovation "Horizon Europe" 2021-2027 (Regulation 2021/695 of the European Parliament and of the Council of 28 April 2021, BOE of 12 May 2021) maintains and strengthens the support for Open Science promoted in the previous Framework Programme H2020:

Article 14. Open Science:

Better dissemination and exploitation of research and innovation results, as well as support for the participation of society.

1. The Programme shall encourage open science as an approach to the scientific process based on cooperative work and diffusing knowledge, in particular in accordance with the following elements which shall be ensured in accordance with Article 39(3) of this Regulation:
 - (a) open access to scientific publications resulting from research funded under the Programme. Beneficiaries shall ensure that they or the authors retain the intellectual property rights necessary to meet open access requirements.
 - (b) open access to research data, including those underlying scientific publications, in accordance with the principle 'as open as possible, as closed as necessary'.
2. The principle of reciprocity in open science shall be promoted and encouraged in all association and cooperation agreements with third countries, including agreements signed by funding bodies entrusted with the indirect management of the Programme.
3. Compulsory Data Management Plan. Responsible management of research data shall be ensured in line with the principles 'findability', 'accessibility', 'interoperability' and 'reusability' (the 'FAIR principles'). Attention shall also be paid to the long-term preservation of data.

Indeed, the sharing of research data should follow a pre-established plan, or data management plan, to guide the whole process. It is a document that describes how research data collected or generated during the course of the study or project will be handled.

The data management plan should include the following elements:

- Roles and responsibilities.
- Data expected to be collected in the research and the nature of the data.
- Data retention period.
- Data format.
- Storage and preservation.

As with scientific publications, there are 2 routes to data publication:

1. The green route consists of publishing the data in repositories. In recent years, specific repositories such as Zenodo (<https://zenodo.org>), general repositories such as Dryad (www.dryad.com) or institutional repositories have been created.
2. The golden route involves storing research data as supplementary material alongside the article on the publisher's platform, or publishing data papers in data journals, i.e. specific journals that publish

papers based on the reuse of data. The disadvantages of this route are a lack of interoperability, little guarantee of future preservation, and unclear policies on what can and cannot be done with the data.

Research data must be properly presented in order to be usable, available and reusable for new research, so when they are released, they must meet certain criteria, identified in the FAIR (findable, accessible, interoperable, reusable) principles, which consist of a set of qualities to make the data:

1. Findable: by assigning a unique and persistent DOI or handle identifier, describing the data with rich metadata, including the assigned identifier, and indexing it in a search resource.
2. Accessible: using standardised communication protocols that are open and free. Where data cannot be open for reasons of privacy, national security or commercial interest, the protocol should allow for authentication and authorisation procedures.
3. Interoperable: metadata should use community-agreed formats, languages and vocabularies, and include links to related information via identifiers.
4. Reusable: metadata should be tagged with attributes that provide contextual information and metadata provenance information. They should use an open, machine-readable licence and standards used by the domain-specific community to enable reuse.

The FAIR principles are derived from the famous statement published in Nature in 2016 (Wilkinson, M., Dumontier, M., Aalbersberg, I. et al. The FAIR Guiding Principles for scientific data management and stewardship. *Sci Data* 3, 160018 (2016). <https://doi.org/10.1038/sdata.2016.18>). They apply to the data and the metadata necessary for their effective implementation (metadata are discussed in the next section). The FAIR principles are subdivided into specific sub-principles for each of the 4 main principles. The implementation of these principles requires the use of specifications, methods and tools both for modelling the necessary metadata (discussed in the next section) and for enriching the data.

The resources provided by the GOFAIR initiative (<https://www.go-fair.org/>) and the Research Data Alliance (RDA) are very relevant. In this case, it is advisable to take into account the specifications of the FAIR maturity model promoted by the RDA (<https://www.rd-alliance.org/group/fair-data-maturity-model-wg/outcomes/fair-data-maturity-model-specification-and-guidelines-0>).

Metadata is “data about data”, information that describes the digital object to which it is linked. In a digital information exchange environment, the role of metadata is to provide details about resources through tags, so that metadata in turn facilitates the search and storage of data.

The description of the data should include information necessary to know: who created the data or the source of the data if it was collected, the typology and format of the data, related data, who can use the data, when it can be used, etc. This detailed description, or “metadata”, is essential for the correct interpretation of the data and should be available with the data when interpretation is needed.

Metadata are a necessary resource for applying the FAIR principles to research data collections.

Other initiatives

Plan S (S for shock) is a Science Europe initiative launched in September 2018 by the cOAlition S, a consortium set up by the European Research Council (ERC) and comprising research funding agencies from 12 European countries (Austria, Finland, France, Ireland, Italy, Luxembourg, the Netherlands, Norway, Poland, Slovenia, Sweden and the UK), as well as the European Commission itself, the Gates Foundation and agencies from Jordan and Zambia.

The main objective of the plan is to ensure that, from 2021, all scientific publications resulting from publicly funded projects are immediately made open access and comply with the ten principles of the plan:

1. Authors or their institutions retain copyright to their publications. All publications must be published under an open license, preferably the Creative Commons license (CC BY).
2. The Funders will develop robust criteria and requirements for the services that high-quality Open Access journals, Open Access platforms, and Open Access repositories must provide.
3. The Funders will provide incentives to establish and support high-quality Open Access journals or platforms in cases where do not yet exist.
4. Open Access publication fees are covered by the Funders or research institutions, not by individual researchers.
5. The Funders support the diversity of business models for Open Access journals and platforms. When Open Access publication fees are applied, they must be commensurate with the publication services delivered and the structure of such fees must be transparent.
6. The Funders encourage governments, universities, research organisations and libraries to align their strategies, policies, and practices, notably to ensure transparency.
7. The above principles shall apply to all types of scholarly publications, but it is understood that the timeline to achieve Open Access for monographs and book chapters will be longer and requires a separate and due process.
8. The Funders do not support the “hybrid” model of Open Access publishing, but they will accept it on a transitional basis within a clearly defined timeframe, and only as part of transformative arrangements.
9. The Funders will monitor compliance and sanction non-compliant beneficiaries/grantees.
10. The Funders commit that when assessing research outputs during funding decisions they will value the intrinsic merit of the work and not consider the publication channel, its impact factor (or other journal metrics), or the publisher.

DORA Declaration

The San Francisco Declaration on Research Assessment (DORA) promotes a change in the impact factor-based system of research assessment. Therefore, other means of assessing research and researchers, with emphasis on the quality of research rather than its publication, are needed: <https://sfdora.org/>

Methodology

An initial diagnosis of the current situation of repository use by IIS was made through a survey of IIS by Repisalud (see Annex 1), interviews with key people and internet searches of indexed repositories.

Development and Results

The main conclusions are as follows:

Analysis of the results of the survey sent by RepiSalud (April 2021).

- The survey was sent to 32 IIS, with a response rate of 87.5%.

- 78.6% of the responding IIS (n=28) use an institutional repository for OA.
- The most common types of repositories used by IIS are those of the Autonomous Communities (39%) and universities (32%).
- The survey did not allow for an in-depth analysis of the technological characteristics of the repositories (questions 4, 5, 6, 7, 8 and 9).
- The user profile of the depositor is mainly the researcher (61% of IIS ticked this option), although deposits are also made by the library and/or research management department.
- The most common types of documents deposited in repositories are “scientific articles”, with 68% of IIS ticking this option, and “clinical practice guidelines” (36%). In terms of document types, there are repositories that do not collect the scientific output of IIS.
- 71% of the IIS have a research management system (CRIS) such as Fundanet or others, although the possibilities of interoperating their systems through metadata (such as OAI DUBLIN CORE or others) are unknown, as well as the technical possibilities of federating their active directory with the ISCIII.

Search in the Andalusian Institutional Health Repository

IBIMA. Biomedical Research Institute of Malaga [163]

IBIS. Institute of Biomedicine of Seville [76]

ibsGRANADA. Biosanitary Research Institute of Granada [87]

IMIBIC. Maimonides Biomedical Research Institute of Cordoba [34]

INIBICA. Biomedical Research Institute of Cadiz [1]

Analysis of the regulatory and strategic framework for OA:

- There are solid policies at European and national level for the development of OA in the European Research Area.
- The main funding agencies promote these policies through their funding instruments (calls for proposals), including in the grant agreements or regulatory bases the conditions to be met for OA to the results that may arise from the funded projects.
- At European and national level, projects are being developed to promote Open Access to health research data (examples include: FAIR4Health, IMPaCT, etc.) which are designing solutions for Open Access of data in this field, closely related to health history.
- The European Commission has calls planned to further deepen and develop the OA policy, so progress will continue to be made on practical aspects for its implementation.

Conclusions from this initial analysis:

- There is a lack of awareness of Open Access tools and resources in the IIS.
- The situation of repositories by IIS is heterogeneous, with institutional repositories at the level of the Autonomous Communities, at the level of the entities participating in the IIS (Universities/ CSIC) and at the level of the Centres. The most common repositories used by the IIS are those of the Autonomous Communities (11/28) and of the Universities (9/28).

- Institutional and/or thematic repositories do not usually include the deposit of research data, although this practice is becoming more widespread.
- The scientific production collected in repositories is scarce and may be affected by problems of correct attribution of articles by institutes.
- Few research outputs are deposited in repositories, the most common being sequencing data.
- The practical application of OA solutions is undergoing many changes, resulting from progress and the allocation of economic resources to this policy.
- It is necessary to analyse the information management processes associated with the publications and research data of the IIS in order to provide a complete, integrated and optimal response to all the needs associated with the use of this information (bibliometrics, dashboards, web, CVN, implementation of Open Access policies, etc.).
- It is necessary to have specific policies and procedures for the publication of research data from the digital health records of partner hospitals, ensuring legal and ethical compliance in the use of such data. These policies must include: anonymisation procedures, authorisations for access, use and publication (if applicable and at the appropriate level) by data protection officers and managers of the participating hospitals, commitments to NO re-identification, data protection impact assessment procedures, and any other ethical and organisational requirements of the relevant healthcare providers.

The situation of the other members of the GT3 working group is included, completing the initial diagnosis by analysing, among other aspects:

- The technical capacity of each institution and the key people involved in Open Access to publications and to data.
- The level of use of repositories.
- The repositories used by each institution —the basic common features and whether they cover the research data repository—, and the standards used for the metadata schema.
- Procedures for automated upload of open access publications.
- Research data deposited in local repositories.
- External data repositories used.
- Capacity for secondary use of care data collected from the digital health records of partner hospitals.

IDIVAL

The Valdecilla Health Research Institute (IDIVAL) has a double repository, that of the University of Cantabria, co-founder of the Institute, which currently contains information on 355 articles, 1 book and 81 research projects. Within this repository, IDIVAL appears as a separate entity in which the Institute's work can be identified (<https://repositorio.unican.es/xmlui/>). The upload is centralised at the University of Cantabria.

The Institute itself has a web-accessible repository in which all published works can be identified, searched by author, group, subject, and which provides access to works in OA, information on the visibility of each of these works, impact on networks, etc. The references are loaded semi-automatically through specific importers

that retrieve the information from the Institute's (IDIVAL) information systems; in this case no preprints are loaded, only access to the original source is given in all cases and, in the case of OA, access is given to the full text. All this information is published on the web, both in the groups and in each of the individuals that make up the Institute, as well as in a specific search engine for publications (<https://www.idival.org/es/Investigaci3n/Publicaciones>).

With regard to the secondary use of health data, a platform has recently been created in the ATLAS system that allows the secondary exploitation of health data (following the model of the EHden consortium (The European Health Data & Evidence Network (EHDEN), born out of the IMI 2 project of the same name).

IIS BIODONOSTIA

The IIS Biodonostia is working to make the field of Open Science visible and to promote the Open Access (OA) culture of its publications. To this end, the Committee for Responsible Research and Innovation (RRI), which aims to bring transparent, high-quality science closer to society, has drawn up the IIS Biodonostia Open Access Guide and Open Science Plan.

With regard to digital infrastructures, the Department of Health of the Basque Government and the IIS Biodonostia are working on the creation of an institutional repository of scientific information, where all the actors of the Basque public health system can deposit the content of their production. This institutional repository will be a useful tool for promoting Open Access through the Green OA route, giving authors the option of making a publication freely available and archiving it.

On the other hand, some of the researchers of the IIS Biodonostia make use of open access repositories such as NCBI, DRYAD or ZENODO, with 59.40% of the genomic projects carried out in 2020 being stored in these repositories.

ISABIAL

1. Technical capacity and key people involved in Open Access to publications and data:

ISABIAL currently relies on the repositories provided by the libraries of the following institutions:

- Virtual Library of the Hospital General Universitario de Alicante (BV-HGUA)
- Library of the Miguel Hernández University (UMH)
- Network of Libraries and Archives of the Spanish National Research Council (CSIC) for the few ISABIAL researchers who physically carry out their activities within the Institute of Neurosciences (CSIC-UMH centre).

As a result, ISABIAL does not have its own repository or staff specifically dedicated to open access to publications and data. There is also currently no explicit policy to promote open access publishing. This means that in 2020, 23.7% (128 / 540) of the publications generated in ISABIAL was open access, a proportion that should be increased.

2. Level of use of repositories:

The use is occasional, at the discretion of the researcher, and subject to the subscription and open access policies of each library. The access tends to focus on documents produced within the institution to which the library belongs.

3. Repositories used, basic common features and whether they cover the research data repository, and the standards used for the metadata schema:

The BV-HGUA is aimed at clinical staff and provides access to general repositories of practical guidelines, bibliographic search engines, inter-library loan for access to publications not included in the subscription, as well as access to public repositories (e.g. related to protocols and research in COVID-19, drug agencies, etc.) and other specialised tools. It is worth highlighting its own initiatives, such as the inclusion of a link to a web page of the Gynaecology and Obstetrics Service, where its research work and practical guides are published, a practice that is not widespread.

The UMH library is similar to the previous one, although it is aimed at the university community. The advantages and necessity of open publication are explicitly mentioned (<https://biblioteca.umh.es/accesoabierto/>) and provides access to the RediUMH digital repository, which includes the UMH's teaching output and all the final degree/master projects (TFG and TFM), the output generated by the university's institutional activity (management, cultural activity, academic events), the scientific output and research activity, including the theses defended at the UMH, the journals published within the UMH, as well as the publications of congresses organised by the university itself and all its bodies. These publications are made available through self-archiving.

Other CSIC libraries can be accessed through the CSIC network. It has its own institutional repository (DIGITAL.CSIC), whose mission is to "organise, preserve and disseminate CSIC research results in open access". To date, it contains 233,589 available records, of which 62.19% are open access. Since 2019, there has been an Institutional Open Access Mandate, which aims to promote open access to research results through institutional repositories, but it affects CSIC staff and therefore has little impact on ISABIAL as a whole.

In any case, all these repositories are limited to publications, with no possibility of storing raw research data and metadata. There does not seem to be a clear policy to include this type of data in the near future.

4. Procedures for automated upload of open access publications:

They do not exist at the institutional level. Each researcher follows their own open access upload policy, the most common being APC (Article Processing Charges) through their own research fund, with the policy of uploading preprints to repositories such as BioRxiv.org still very rare due to suspicion. There are also direct uploads to researchers' own profiles on platforms such as ResearchGate. These improve the dissemination of publication results but do not represent a real improvement in terms of open access, as publishers' conditions must be respected.

5. Research data deposited in local repositories:

There are no local repositories. ISABIAL has its own server to increase computing capacity, but not for permanent data storage.

6. External data repositories used:

Only the NCBI repository (Gene Expression Omnibus, <https://www.ncbi.nlm.nih.gov/geo/>) is used for uploading genomic, transcriptomic and epigenomic data by the few researchers using omics approaches in their work.

7. Capacity for secondary use of care data collected from the digital health records of partner hospitals.

Such use is not envisaged outside the research group collecting this type of data as part of their research. Membership of national networks allows authorised users to enter network datasets, as in the case of the CIBER de enfermedades hepáticas y digestivas (CIBER-EHD) within ISABIAL.

IDIPHISA

The Health Research Institute of the Puerta de Hierro – Segovia de Arana (IDIPHISA) has been using the Institutional Repository of the Regional Health System of the Community of Madrid (<https://repositoriosaludmadrid.es/>) since 2020. This repository is an open digital space whose purpose is to collect, preserve and disseminate the scientific production of all its professionals as a result of their health, teaching and research activities. The Virtual Library of the Health System of the Community of Madrid is in charge of managing the Institutional Repository, which is designed as a service within it. It is part of Open Access, an international movement that promotes open access to scientific literature, favouring the dissemination and increasing the visibility of the work developed by researchers, thus contributing to free access to scientific knowledge.

The scientific output in this repository is classified according to the type of document, resulting in eight collections:

- Articles
- Congress communications
- Research data
- Disclosure Documents
- Training and teaching material
- Reports and technical documents
- Books and book chapters
- Multimedia material

The documents contained in the repository are available on open access for viewing and downloading by all users, without the need for registration or prior authorisation. Any reuse of the data must comply with the conditions laid down in the licences of use. In all cases, authorship must be acknowledged by means of a bibliographic reference and a link to the full text.

The repository allows documents to be deposited in three ways:

- Self-archiving: The author carries out the deposit by completing a form that describes the work, uploads the full text file, and accepts the non-exclusive distribution licence of the Repository. Once the process is complete, the document must be checked and approved by a validator before it becomes publicly visible.
- Delegated deposit: This is carried out by a third party at the request of the author, who has the appropriate permissions granted by the repository administrator. The author wishing to use this service must contact the authorised person at their centre and provide details of the work, the file containing the text of the document and the signed non-exclusive distribution licence.
- Bulk Upload: In exceptional circumstances, the repository administrator may deposit documents in bulk, provided they are under open licences such as Creative Commons or similar licences that allow unrestricted online sharing and distribution, without the explicit consent of the authors.

IIS– Fundación Jiménez Díaz

The Fundación Jiménez Díaz Institute has defined its Open Science policy.

Repositories used, basic common features and whether they cover the research data repository and the standards used for the metadata schema:

The repositories where data is currently being uploaded are:

BIOBANCO, BioProject (<https://www.ncbi.nlm.nih.gov/bioproject/>), ClinicalTrials.gov (<https://www.clinicaltrials.gov/>), ClinVar (<https://www.ncbi.nlm.nih.gov/clinvar/>), Collaborative Spanish Variant Server (<http://csvs.babelomics.org/>), EU Clinical Trials Register EudraCT (<https://www.clinicaltrialsregister.eu/>), European Genome-Phenome Archive (EGA), European Nucleotide Archive, ENA (<https://www.ebi.ac.uk/ena/browser/home>), European Union Drug Regulating Authorities Clinical Trials Database (<https://eudract.ema.europa.eu>), Flow Repository (<http://flowrepository.org/>), GEO DataSets: (<https://www.ncbi.nlm.nih.gov/gds/>), International Standard Randomized Controlled Trial (ISRCT; <http://www.isrctn.com>), NCBI Sequence Read Archive, SRA (<https://www.ncbi.nlm.nih.gov/sra>), PROSPERO (<https://www.crd.york.ac.uk/prospero>), ProteomeXchange Consortium (<http://www.proteomexchange.org/>), Digital Repository of the UPF (<https://repositori.upf.edu/>).

Procedures for automated upload of open access publications:

We have no automatic procedure in place.

Capacity for secondary use of care data collected from the digital health records of partner hospitals.

This is already being done in observational studies at the IISFJD.

Conclusions and Suggestions

This section contains the proposals and recommendations made by the working group for the IIS to comply with the Open Access mandates, overcoming the obstacles or shortcomings identified:

- To analyse existing examples and tools so that all biosanitary research institutes in Spain can access a repository of publications and data in the shortest possible time.
- To promote open publication. There are several possibilities to be explored:
 - Inclusion of an item for funding Open Access in the applications for ISCIII grants.
 - By partially subsidising the costs of Open Access publication.
 - In any case, the institutes themselves should evaluate the promotion of internal OA policies, beyond fulfilling one of the requirements for re-accreditation as an IIS.
- To facilitate open data diversity. Access to research data is currently dominated by omics data: genomic, transcriptomic, epigenomic, metabolomic, proteomic, etc., but data from imaging techniques highly relevant to translational research, such as magnetic resonance imaging and immunohistochemistry, whose growing volume would allow the application of deep learning and artificial intelligence tools, must also be considered.
- To ensure, both in the institutes and in the ISCIII, a Data Sharing policy for the repository that governs the use of deposited research data.

- To establish a clear and strong policy on OA, covering both Open Access to scientific publications and Open Access to research data. This policy will be in line with Horizon Europe and will advocate that all Open Access scientific output from IIS is deposited in a repository, and that research data resulting from publicly funded projects are deposited in repositories. This policy will be widely disseminated to raise awareness among researchers of the new paradigm of Open Science.
- To develop incentives to support the implementation of Open Access to publications and research data. In this sense, the completion of a project could be linked in the final reports to the obligation to deposit the research data in a repository, provided that a data sharing policy has been established beforehand.
- The possibility for IIS that do not have an institutional and/or thematic repository in their environment, whether their own, that of their autonomous community or university, or that do not cover the deposit of research data, to use the ISCIII Repisalud.
- Convergence of the different repositories into a common one (e.g. Repisalud – ISCIII).
- To provide training and technical advice to researchers on Open Access and the management of research data in projects.

Suggestions:

- Developing training activities for researchers on the procedures and repositories to be used, data protection and European Open Access requirements.
- Depositing all scientific publications resulting from publicly funded projects, both at Spanish and EU level, in repositories.
- Implementing the necessary infrastructure to deposit research data resulting from publicly funded projects, both Spanish and EU, in repositories according to the FAIR principles.
- Aligning and converging IIS institutional policies on Open Access with the European framework.
- Drawing up a practical guidance document, including what can be done, where, list of repositories, etc.
- Ensuring the connectivity of the different repositories of the Autonomous Communities or institutions with Repisalud.

Gender Perspective at Health Research Institutes

GT4. *Institute Partnership*.2021.

Coordination: IDIBELL.

Manager: Dr. Gabriel Capella Munar. General Director of IIS IDIBELL.

Executive Summary

This document is intended as a position statement to help define standards of compliance with gender policies in Health Research Institutes (ISS) and to support their implementation. Based on an analysis of both the internal context, based on data from surveys of IIS, and the external context, two main problems are identified: the loss of female talent throughout the research career, also known as 'gender scissors', and the low representation of women in leadership positions. The main factors perpetuating these inequalities include unfavourable working conditions, the pay gap and the lack of effective policies on work-life balance and shared responsibilities. Furthermore, there is little evidence of gender perspective in the assessment and implementation of research projects, which reinforces gender bias in disciplines such as biomedicine.

Based on the diagnosis of the current situation, the working group proposes a series of recommendations to be implemented in the Institutes, such as the allocation of resources for gender equality, the implementation of balanced selection committees and the inclusion of gender in the evaluation of staff. Medium- and long-term actions are also proposed, including the creation of consultative bodies and a visibility campaign to position the ISCIII as a leader in gender equality at the international level.

Introduction

The R&D&I sector in Spain is a feminised sector in terms of gender issues. However, the situation regarding gender equality in science and innovation in the health sector is not very different from the general situation in our society in terms of professional development and leadership opportunities. In this sense, the research system is not gender balanced and needs a boost to accelerate change and correct the current situation.

Theoretical Framework

There are reasons, to a greater or lesser extent, for the current lack of gender balance in science and innovation. The main causes are identified below:

Working conditions:

- Obstacles to research careers. The lack of definition of a research career in IIS affects both men and women. In the case of women, these obstacles are exacerbated by a greater tendency to take leave to care for children and/or other dependants, certain necessary leaves during pregnancy, and the maternity leave, which is now equal to paternity leave, but transferable between parents. Traditionally, women have been more committed to family co-responsibility tasks than their male partners, which has affected their availability for longer international research stays and even, in other IIS, their ability to lead competitive research projects. In short, it has affected the most tangible results of research activity, such

as scientific output and R&D transfer. This situation often results in a lack of promotion to leadership positions.

- Possible pay gap, both vertical and horizontal. In terms of the vertical scale, the continued promotion of men to the highest positions of responsibility in the IIS necessarily implies a salary pyramid in which women receive lower salaries because they do not reach management and leadership positions. In horizontal terms, for positions of equal value and responsibility, this analysis must be carried out in depth, using the salary records and annual salary audits required by law (RD 902/2020) for all companies with a Gender Equality Plan. IIS are part of this legal framework and must collect this data. Therefore, it is important to start measuring these parameters so that, if there is a gap, it can be highlighted, and corrective action can be taken.
- Lack of work-life balance measures and a culture of co-responsibility for parenting and care.

Gender Perspective:

- Insufficient integration of the gender perspective in the evaluation of research and innovation. It would be appropriate to take into account the periods linked to maternity and paternity in merit and curricula, their impact on the formation of work teams, scientific production and results, access to funding, etc. On this point, we would like to point out that in the evaluation processes developed by other agencies, such as ANECA or AEI, measures are already in place to promote gender equality and to try to minimise the impact of maternity on female researchers (it should be remembered that the paternity/maternity leave of the other parent was not equal until 2021).

As these leaves are divisible and transferable for both, the woman usually requests a continuous period of absence, while the other parent divides his leave into 2 or more periods, allowing greater flexibility and work adaptation than in the case of the woman).

- Little or no consideration of the gender perspective in research and innovation projects, according to Responsible Research and Innovation (RRI). Little or no consideration of the gender perspective in research activities in all scientific disciplines, but especially in the field of biomedicine, where the majority of treatments, new drugs or therapies are based on male biology/nature and where the "reproducibility-of-the-role effect" occurs, leading to voluntary or involuntary biases in the definition of working hypotheses and the selection of study subjects.

Culture and Awareness:

- Organisational cultures with low sensitivity to gender equality.
- Unconscious gender bias and perpetuation of roles and stereotypes.
- Lack of gender awareness and training.
- Missed opportunities to integrate new approaches to research, team management and leadership.
- Lack of economic resources in institutions to promote gender equality policies and to recruit professionals with gender equality expertise to manage them.
- Lack of political will to adopt policies that promote gender equality.

It should be noted that, in addition to gender, strategies for integrating intersectionality and diversity into equality policies should also be addressed.

Methodology

In order to produce this positioning report, the working group has held group meetings to present and agree on the actions to be taken. The sequence was to identify the current situation, analysing the internal and external context, with the aim of making a diagnosis in order to draw conclusions and propose a series of recommendations.

In order to analyse in more detail the current reality of research centres in Spain from a gender perspective, two specific surveys were carried out¹ (Annex II), designed taking into account the scientific and research environment and its specificities, which made it possible to draw up an updated diagnosis and a quantitative and qualitative vision of the quality of IIS in terms of gender equality.

On the other hand, existing initiatives carried out by external bodies that are part of the R&D&I ecosystem, such as AMIT and the Observatory for Women, Science and Innovation, were identified.

The IIS Accreditation Assessment Guide and the Monitoring System were also reviewed, analysing the sections that currently include a gender perspective.

Once this information had been compiled, and as a result of the analysis of the initial situation and the reflections carried out in the IIS, a series of recommendations were drawn up with the aim of helping to define and implement gender policies in the institutes.

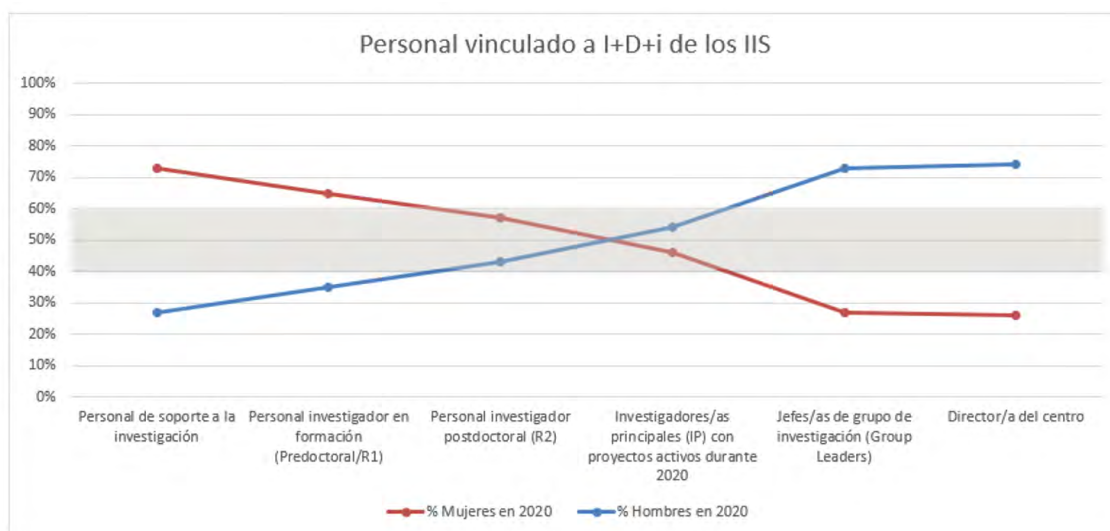
Development and results

Survey to the IIS. Scissor-shaped curve

The Gender Perspective Working Group of Foro IIS has carried out a survey into the health research institutes accredited by ISCIII.

The survey was sent to the 31 institutes through the ISCIII in July 2021, and a reminder with an extended deadline for response was sent at the beginning of September. The response rate was 68% (21 institutes).

The results are presented below in both graphical and tabular form:



¹ The data obtained from the IIS for the preparation of this report refer to the year 2020.

Personal vinculado a I+D+i de los IIS	% Mujeres en 2020	% Hombres en 2020
Personal de soporte a la investigación	73%	27%
Personal investigador en formación (Predoctoral/R1)	65%	35%
Personal investigador postdoctoral (R2)	57%	43%
Investigadores/as principales (IP) con proyectos activos durante 2020	46%	54%
Jefes/as de grupo de investigación (Group Leaders)	27%	73%
Director/a del centro	26%	74%

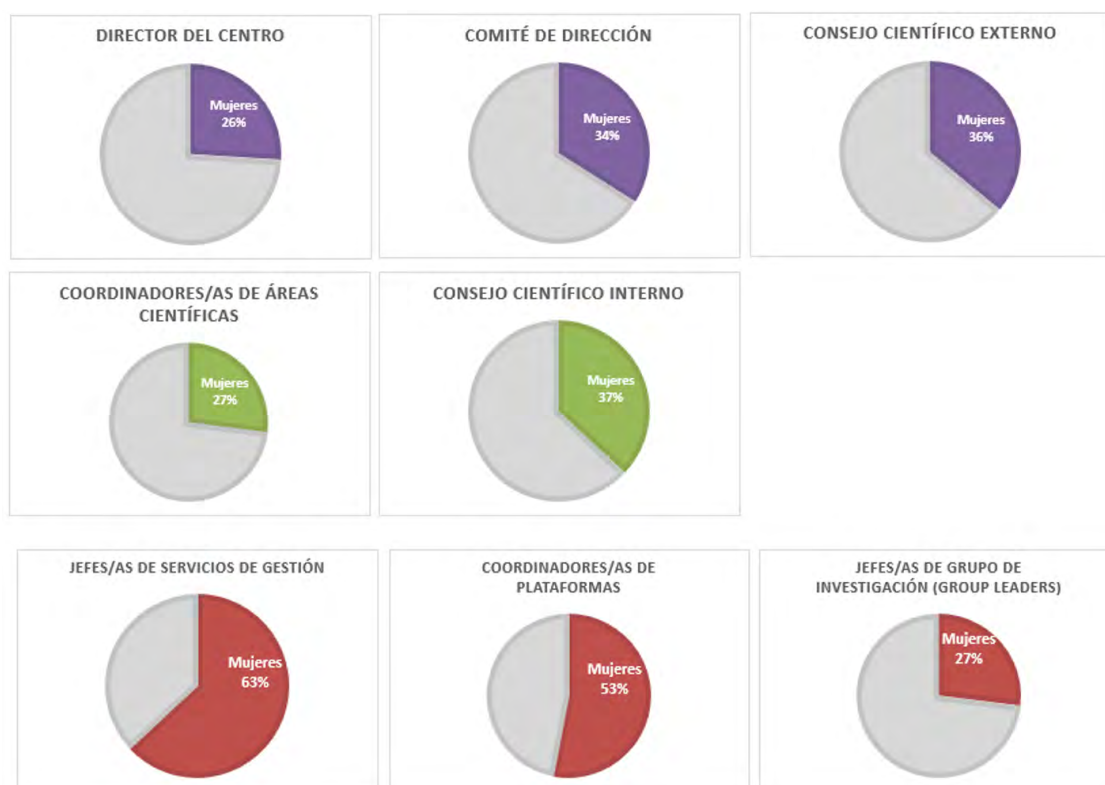
Survey to the IIS. Female leadership in decision-making positions

The Gender Perspective Working Group of Foro IIS has carried out a survey into the health research institutes accredited by ISCIII.

The survey was sent to the 31 institutes through the ISCIII in July 2021, and a reminder with an extended deadline for response was sent at the beginning of September. The response rate was 68% (21 institutes).

The results are presented below in aggregated graphical form:

Data 2020 – Health Research Institutes



Review of the IIS Accreditation Assessment Guide and Monitoring System

A review of the current Guide and the indicators that make up the current IIS Monitoring System was conducted from a gender perspective. The sections that take gender into account are identified.

Governance:

- The gender composition of the governing bodies, the internal and external scientific committees and the heads of research programmes or areas are monitored annually.

STRATEGY, CAPABILITY AND SCIENTIFIC PERFORMANCE:

Human resources:

- 2.2.2.1 Specific actions for female leadership should be developed in the IIS HR Plan.
- 2.2.2.3 The IIS HR Plan must include actions for gender equality:
 - Equal opportunities and equity issues in research careers.
 - Considerations in the recruitment policy for research, technical, management and other services staff.

Aspects of representation in the different bodies and committees.

- 2.2.2.6 Adherence to the HRS4R Charter and Code of Conduct, which includes gender aspects.
- 2.2.2.8 Obligation to evaluate the Equality Plan every two years.
- 2.2.2.10 to 2.2.2.12 HR indicators disaggregated by gender (Principal Investigators, R1, Primary Care...).

Raising of resources for research:

- 2.2.3.1 to 2.2.3.6 Indicators on funding raised segregated by gender.

Annual scientific report:

- 2.2.6.1 An annual scientific report including a gender perspective is produced.

Shared scientific project:

- 2.3.1.4 The CCP will include actions to promote the integration of the gender dimension in the content of the research and innovation under development.

Current situation of the R&D&I ecosystem

Main actors in the ecosystem

The proposed actions to promote gender balance are a shared responsibility. Some of them require the public and private funding bodies (European Commission, Ministry of Science and Innovation, ISCIII, ...) to define compatible and complementary policies that incorporate the gender perspective.

However, in other cases the scope is limited to the institutions themselves, which can promote and implement measures for effective equality between women and men in the workplace to a greater or lesser extent, as well as include agents/committees to monitor it.

Other actors can also influence the promotion and implementation of gender equality, such as associations, scientific networks and cooperating companies. It should be noted that this aspect is mentioned in the strategic documents of the R&D&I network in which the IIS are involved, such as the Spanish R&D&I strategy and the strategies of the Autonomous Communities.

Initiatives of the R&D&I ecosystem

The European Institute for Gender Equality (EIGE), which studies and measures the progress of EU countries towards gender equality through the Gender Equality Index, estimated that it would take 50 years to achieve gender equality. However, in its latest 2020 report, it has increased this to 60 years. The reason for this delay is that policies are not being implemented effectively or quickly enough. As a result of the situation described above, various bodies have launched initiatives to accelerate gender equality and incorporate gender

perspective. In addition, the main public funders of research have included gender perspective requirements in their competitive calls. This is the case of the Ministry of Science and Innovation, the Institute of Health Carlos III and the European programme Horizon Europe, all at national and international level, although other private and/or regional funders are also involved. Another reference to be taken into account are the principles of the Code and the Charter of the HR Strategy for Researchers (HRS4R), which includes gender aspects in its policies in order to obtain the label of excellence in human resources management in the field of research.

Observatory for Women, Science and Innovation (OMCI) Work Programme 2021-2022

At the end of 2020, the OMCI adopted a work programme focused on the following five priority action areas:

- a) Consolidating a system for collecting, monitoring, evaluating and disseminating gender statistics and indicators in R&D&I;
- b) Promoting the career stability of women researchers;
- c) Implementing joint actions to increase the visibility of women in science, technology and innovation and to progress towards a balanced presence in all fields and at all levels;
- d) Promoting changes towards gender equality in the organisational culture of R&D&I centres;
- e) and highlighting the gender dimension as a specific area of study and research, as well as a cross-cutting issue to be included in R&D&I projects.

Analysis of areas for action

This section proposes actions that can be carried out in the IIS to correct the situation of inequality into the following areas:

- a) Working conditions – Organisational measures:
 - i. If a pay gap is identified in the IIS, measures should be taken to reduce and/or mitigate it, such as:
 - i. Systematising the pay policy on the basis of a job evaluation from a gender perspective.
 - ii. Breaking down the concepts that make up pay perceptions to identify the reasons for any gap.
 - ii. Implementing work-life balance measures such as:
 - i. Encouraging and disseminating co-responsibility among employees for care tasks.
 - ii. Periodically adapting changes/advances in policies related to equality and/or that represent improvements in work-life balance measures.
 - iii. Defining channels or ways to find out the needs of employees in terms of work-life balance.
 - iii. Implementing measures against gender-based violence in the workplace, such as discrimination and sexual harassment based on gender and sexual orientation. And ensuring sexual freedom for employees.
 - iv. Occupational health. Studying the causes that mainly affect workers in the workplace according to their gender and including a care protocol that takes these causes into account in the existing obligation of companies to provide an occupational health service to their staff.

- v. Allocating a budget line for the promotion of gender equality, both for the promotion of actions and for the assignment of specialised staff to the management of gender equality in institutions (gender equality officer/unit).
 - vi. Encouraging the creation of gender equality structures (working groups and/or commissions). Creating gender equality working groups and/or commissions composed of members of the institutions (and/or external consultants) to advise on gender equality issues.
 - vii. Promoting coordination in order to align the gender policies of the IIS with those of the hospital centres and associated universities.
 - viii. Mentoring/training for the acquisition of leadership training with female leadership characteristics for each level of the research career.
- b) Promotion of gender balance:
- i. Using gender balance criteria in the selection of research teams, management positions and decision-making bodies.
 - ii. Ensuring gender balance in the composition of assessment committees.
- c) Monitoring and assessment. Information (indicators, data, etc.) should be presented and analysed in a holistic and gender-disaggregated way. This makes it possible to identify weaknesses and strengths and helps to make decisions about improvement measures.
- d) Awareness raising and organisational culture:
- i. Training and capacity building to identify and address gender bias and promote cultural change.
 - ii. Visibility:
 - a. Obtaining a formal and public commitment from the governing bodies of the institutions (public funding bodies) and the IIS to the importance of implementing these actions.
 - b. Promoting actions (campaigns, networks, initiatives, exhibitions, conferences, round tables, etc.) to increase the visibility of women in science and to promote the female reference point and scientific vocations.
 - iii. Establishing a permanent gender working group to carry out active and coordinated gender monitoring and policy in the IIS.
- e) Incorporation of gender perspective:
- i. Promoting the integration of sex/gender analysis in the content of research projects (including clinical trials) and innovation, whenever relevant, to avoid gender bias.
 - ii. Promoting research on women's health with specific projects, lines or working groups focusing on pathologies with a higher prevalence in women, or where gender is a relevant variable for prognosis, diagnosis, study and/or treatment.
 - iii. Incorporating the gender perspective in the assessment of research staff and research groups.
 - iv. Promoting the creation, dissemination and use, where possible, of a CV anonymised in gender, origin and age.
 - v. Establishing scientific reward schemes for IIS and other R&D&I institutions that consider and actively promote the gender perspective and achieve objective and quantifiable results.

Conclusions/Suggestions

As a result of the analysis in the previous sections, the following actions are proposed, classified according to those actions that should already be implemented (or should be implemented in the short term) in the IIS, those actions that would be desirable to implement and, finally, a set of aspirational actions aiming at more ambitious objectives in terms of equality and gender perspective.

Aspects that should be in place or implemented in the IIS in the short term

- Equality Plan with at least the content required by the applicable legislation and by the usual funding bodies (national and international), and which allows for the rapid incorporation of equality-related measures that are modified by law.
- Protocol for action and prevention of discrimination, and sexual or gender-based harassment (as part of the Equality Plan required to the IIS). In this respect, the ISCIII could develop a model to facilitate implementation and ensure that it is homogeneous. Other model documents could also be developed, such as: Equality Diagnosis, Equality Plan, Equal Pay Protocol and Pay Audit, Anonymous CV...
- Measures to identify and, where appropriate, eliminate the pay gap (including monitoring) in accordance with Royal Decree 902/2020 of 13 October on equal pay for women and men.
- Female leadership models with their own characteristics and their use in the R&D&I system.
- Assessment and monitoring:
 - Monitoring gender scissor-shaped curve.
 - Continuing to monitor the gender composition of committees, advisory bodies and governing bodies. Defining criteria for composition where possible.
 - Disaggregating by gender the Centre's indicators of research activity and transfer.
- Promoting mandatory equality training for all IIS staff and include it in management training programmes. Defining a common programme for all IIS with the support of the Ministry.
- Mentoring programmes with the identification of leaders to accompany young female researchers.
- Mandatory training on gender bias for staff of evaluation committees (AMIT).
- Evaluation of the gender perspective in projects, both in the working team and in the hypothesis presented, in internal calls (financed by the IIS itself) and external calls (financed by the ISCIII).
- Assessing the coordination/alignment of the gender policies of the hospitals and universities with the IIS. Mapping the situation in the different Autonomous Communities / Regional Health Systems.
- Updating of the IIS Accreditation Assessment Guide and Monitoring System. It is proposed to maintain the existing sections related to the gender perspective and to complement them with the following proposals:

Strategy, Capability and Scientific Performance:

Strategic Plan:

- 2.1.1.1 (section referring to the IIS Strategic Plan): It is proposed that gender equality be elevated to its own strategic objective in the IIS Strategic Plan.

- 2.1.1.2 (section referring to the IIS Strategic Plan): It is proposed that gender equality be considered as a relevant axis in the evaluation of the IIS like the other three current axes (translational research, innovation and international positioning).
- 2.1.2.1 (section referring to the monitoring of the IIS Strategic Plan): It is proposed that there should be indicators in the SP to monitor aspects of gender equality.

Human resources:

Reference is made to the fact that the IIS must have an Equal Opportunities Plan, but it should be mentioned that it must also have a Protocol for Action and Prevention of Gender Harassment, as set out in Organic Law 3/2007 and RD 901/2020.

It is necessary to consider requesting an indicator on gender-disaggregated payment and on the existence or not of a pay gap or difference.

Training:

It is necessary to consider training on gender equality at a strategic level and calculate the number of trainings and people trained on gender equality. Training on awareness-raising, gender bias elimination, management training, etc.

It is necessary to consider requesting annual indicators on gender training (currently not monitored):

- % female students vs. total
- % female lecturers vs. total
- % female speakers vs. Total
- Number of sessions with gender perspective content in R&D+i

Presentation and promotion of intramural institutional gender actions that can be extrapolated to all IIS.

Indicators of transfer to the productive system:

It is necessary to consider disaggregating by gender the indicators on patents, protection and spin-offs for visibility and monitoring of knowledge transfer with a gender perspective.

Review of some of the Criterion 3 Impact indicators where a gender perspective can be included: visibility and dissemination actions, innovation in processes with a gender perspective, transfer products and transfer of results with a gender perspective (related to point 2.3.1.4 of the Evaluation Guide –Shared Scientific Project). It is necessary to distinguish between indicators with an informative purpose for the assessment and monitoring of progress in terms of gender equality and those that would have an impact on the assessment.

Annual report:

It should include appropriate visualisation of data related to the gender gap (e.g. Gender scissor-shaped curve) by promoting the visualisation of the evolution of data over the last five/three years. This type of analysis makes it possible to carry out prospective studies to support decision-making and the definition and implementation of policies. In this sense, it is important that the indicators are traceable, appropriately defined and aligned with those required by SICTI.

Shared scientific project:

The inclusion of scientometric indicators by gender should be considered: Scientific production, resource raising, transfer and another by category/profile of research staff.

Aspects that it would be desirable to implement in the IIS

- Allocating a budget line for the promotion of gender equality, both for the promotion of actions and for the assignment of specialised staff to the management of gender equality in institutions (gender equality officer/unit).
- A composition of selection committees for the selection of posts with a minimum 4:6 W:M ratio. In the case of a selection committee of 3 persons, the ratio would be 1:2.
- Promotion of gender equality to ensure equal opportunities in the final selection phase for R3 and R4 researcher positions.
- Promotion of the integration of gender analysis in the content of research and innovation.
- Promotion of gender balance in research teams (tie-breaker criterion included in Horizon Europe).
- Training/awareness raising: Mandatory tutoring/training/mentoring programmes with gender perspective.
- Incorporation of the gender perspective in the assessment of research staff and research groups.
- Establishment of a permanent IIS working group on gender issues.
- Promotion of equal, inclusive and non-sexist corporate communication in all centres.

Aspirational aspects

- It is proposed to set up consultative bodies linked to the ISCIII with the aim of obtaining information on the critical and most relevant issues that are considered to be addressed in terms of gender equality. These consultative bodies would include internal actors of the ISCIII as well as associated external actors, such as:
 - R1-R4 research staff.
 - Associations (e.g. AMIT), scientific societies and universities.
 - Knowledge transfer experts, training experts, evaluators of national and international calls...
 - Any other group of people identified as relevant for the progress of the gender perspective.
- An annual or biennial inter-institute conference where all IIS can share their experiences:
 - gender equality initiatives
 - gender equality progress
 - Research and innovation projects with a gender perspective
 - Research and innovation projects on women's health
 - Examples of women's leadership
 - Visibility of the achievements of women researchers
 - Specific training with a gender perspective in R&D&I
 - Actions and forum to promote scientific careers among girls and young women
 - Strategic synergies to work together and raise national and international funding in gender-sensitive calls for proposals.

- A strong visibility and advertising campaign for the gender strategy of the ISCIII and its IIS to position it as a leader and reference at national and international level.
- It is necessary assessing whether the (re)accreditation of the HRS4R label is using the gender perspective in depth, in order to consider whether it is necessary to create a logo/label that combines the concepts of science and gender equality and is a sign of effective promotion and implementation of the gender perspective in the IIS.

IIS Activity Monitoring System: review of indicators

GT5. *Institute Partnership*. 2021.

Coordination: IRYCIS

Manager: Dr. Maria Laura García Bermejo. Scientific Director of IRYCIS.

Executive Summary: Towards more useful and realistic indicators

Objective: The GdT5 working group, composed of 13 institutes: IBIS, IMIBIC, IMIB, I+12, ARAGON, BIOCRUCES, IISPDH, IBIMA, INIBIC, IDIBAPS, VHIR, IDIBELL and IRYCIS (coordinator), has carried out, during the year 2021, a thorough review of the current indicators used to measure the scientific activity and knowledge transfer of the IIS, in particular the Monitoring System (“Cuadro de Mandos, CM”) and the Technical Evaluation Guide (GTE). The aim of this reflection and review was to simplify and improve these indicators so that they more accurately reflect the actual work and contributions of the research institutes.

Activities and tasks:

1. Review of the Monitoring System (CM): The CM indicators were analysed in detail, with suggestions and clarifications made for each one. This review was the most immediate and priority task of the group.
2. Review of the Technical Evaluation Guide (GTE): The work was divided into three sub-groups to review the indicators related to scientific activity, internationalisation and impact, and peculiarities. This second task was finally entrusted to the Commission for Technical Evaluation (CTE) and the Programme for Evaluation and Accreditation of Health Research Institutes (PEASIS).

Conclusions and suggestions:

- Less is more: To reduce the number of indicators to those that are strictly necessary and accurately reflect the activities of the IIS.
- Fair comparisons: To ensure that indicators are measured in the same way across all institutions so that they can be compared fairly.
- Clear definitions: To use the same indicators in the evaluation and accreditation of institutes (GTE) as those used in the CM to avoid confusion.
- New indicators on reflection: To consider the inclusion of new or complex indicators if they are well defined, commonly used and reflect the dynamism and evolution of the IIS over time.
- Necessary adjustments to thresholds: To revise the thresholds and expected levels of excellence for some indicators to make them more realistic.
- Duplication in the information provided by the IIS: To simplify the collection of data, in particular on knowledge transfer, to avoid the need for IIS to provide the same information to several bodies.

In summary, this revision exercise proposes to make the indicators simpler, more useful and more reflective of the reality of scientific activity, thus facilitating the assessment and monitoring of the research institutes’ work by any competent body.

Introduction: Assessing excellence in health research as a pillar for competitiveness and advancement of the Spanish Health System

The Health Research Institutes (IIS) in Spain are a fundamental pillar for the promotion of biomedical and health research, not only at the national level, but also in the international competitive arena. These centres of excellence, dedicated to the generation of knowledge and its translation into clinical practice, play a crucial role in the development of science and health policies that promote the health and well-being of the population.

By establishing a rigorous accreditation and monitoring process for IIS, Royal Decree 279/2016 recognises the importance of ensuring the quality and relevance of their research work. In this framework, the Annual Monitoring System (CM) of Indicators and the Technical Guide for the Evaluation and Accreditation of Institutes (GTE) emerge as strategic tools to assess the performance of these centres and guide their continuous improvement.

These regulatory tools go beyond initial accreditation and establish a monitoring system to ensure that standards of excellence in research are maintained. By evaluating key indicators in areas such as scientific production, international collaboration, the impact of results and the uniqueness of each institute, the aim is to strengthen the competitiveness of the Spanish research system and its contribution to global scientific excellence.

In addition, the evaluation of IIS focuses not only on the generation of knowledge, but also on their ability to transfer it to clinical practice and society. In this way, IIS actively contribute to the development of evidence-based health policies, improving the quality of health care and promoting health innovation.

This document presents an analysis and review of these indicators with the aim of refining their capacity to reflect the complexity and dynamism of IIS. Through a participatory process involving all IIS, the aim is to ensure that the indicators are not only relevant and accurate, but also useful for guiding strategic decision-making and promoting excellence in biomedical and health research in the IIS and in Spain, thereby consolidating their position in the international scientific environment.

Theoretical Framework: Review of results through the Monitoring System and the Technical Guide for the Evaluation within the Programme for Evaluation, Accreditation and Monitoring of IIS (PEASIIS-ISCIII).

The PEASIIS-ISCIII aims to consolidate health research centres, anchored in the National Health System, as engines of knowledge generation and transfer. Its objective is to promote innovation in response to Spanish and European health priorities.

Accredited Health Research Institutes (IIS) are characterised by their focus on health needs, both individual and social. They have effective governance that ensures they have the resources and capacity to fulfil their mission: to generate scientific knowledge that, when translated, has a positive impact on individual and collective health. All this within the framework of responsible research and innovation and open science, as recommended by the European Union.

It is important to highlight the following aspects of the IIS assessment process:

- Objective: To ensure that the IIS has effective governance, a solid strategy, adequate resources and scientific outputs that have a positive impact on health.

- Procedure: The constitution, performance and results of the IIS research groups and support units is assessed. The orientation towards the needs of the population, transparency, ethics, scientific quality of results and innovations in health care are analysed.
- Tools: The evaluation is based on the IIS Technical Evaluation Guide (GTE) and complemented by the Monitoring System (CM).
- Implementation: The assessment is carried out through a in-person audit by teams appointed by the ISCIII. The resulting report, together with the documentation, is submitted to the IIS Evaluation Commission, which issues a favourable or unfavourable report.
- Legal framework: The entire process is regulated by Royal Decree 279/2016.

The Monitoring System (CM) as a monitoring tool: In this context, the CM becomes a key tool for continuous monitoring of the IIS after accreditation. It makes it possible to monitor compliance with the GTE criteria and to assess whether the Institute is maintaining the required standards of excellence.

The review of results through the Monitoring System allows:

1. To verify compliance: Verifying that the IIS continues to meet the GTE criteria and maintains its commitment to continuous improvement.
2. To identify strengths and areas for improvement: Identifying areas in which the IIS excels and those that require attention to optimise performance.
3. To inform decision making: Providing valuable information for strategic decision making at both IIS and ISCIII levels.
4. To promote transparency and accountability: Promoting transparency in the management and use of public resources allocated to health research.

In conclusion, the Monitoring System is positioned within the PEASIIS-ISCIII framework as an essential tool for the monitoring and continuous improvement of IIS, ensuring that these centres fulfil their mission to generate high-impact scientific knowledge for the benefit of society.

Methodology

The GdT5 working group, which carried out the review of the CM indicators, was composed of the following institutes: IBIS, IMIBIC, IMIB, I+12, ARAGON, BIOCRUCES, IISPDH, IBIMA, INIBIC, IDIBAPS, VHIR, IDIBELL and was coordinated by IRYCIS (see Appendix I, Excel document on the composition of the GdT5). The GdT5 developed its activities throughout the year 2021, from May to December. The final consensus document of GdT5 was finalised by the IIS Partnership at the end of December 2021, following input from all its constituent IIS and the rest of the IIS.

Initially, 2 tasks were set for GdT5: 1) review of the Monitoring System (CM), and 2) review of the criteria of the Technical Guide for the Evaluation and Accreditation of Institutes (GTE). However, the consensus document of GdT5 finally only included Task 1, the review of the CM.

The group was proposed by the ISCIII in May 2021 and the coordination (IRYCIS) worked on its effective launch and constitution, which took place in a first online meeting on 3 June 2021.

This first meeting was attended by the scientific directors of all the IIS that formed the GdT5 listed above, as well as all by the management staff designated by the scientific directors, involved in the exploitation of the indicators of the IIS and responsible for the annual configuration of the CM in each IIS. The final list of members of the group is attached in Appendix I.

Four online meetings were held with the group, organised and hosted by the Coordination (IRYCIS) on 3 June, 20 July, 28 September and 19 October, and minutes were taken of all of them, which are attached as additional information to this document (see Appendix 4).

In the first meeting, the Coordination established the workflow and provided an Excel document listing all the CM indicators for each IIS in order to analyse, reflect on and propose revisions, if considered necessary. In subsequent meetings, the various proposals were discussed and agreed upon until the final group document was completed. It is important to mention that halfway through the process, the coordinator of GdT5, IRYCIS, held a meeting with PEASIS to assess the work done so far in the group and to redirect some aspects. At all times, the GdT5 Coordinator was open to contacts with the different IIS in order to clarify doubts and make progress.

Finally, the final document agreed by GdT5 was open for reflection and suggestions from the rest of the accredited IIS during the month of November. In December, after the incorporation of the contributions of the other IIS, the document was finished and briefly presented by the Coordination (IRYCIS) at the meeting of the IIS Partnership held on 16 December 2021. The ppt of this presentation is attached in Appendix IV as additional documentation.

On 21 December 2021, the last communication was sent by email from the coordination (IRYCIS) to the rest of GdT5, attaching the final consensus document in pdf and the above presentation. Appendix IV also contains the last communication email and the final document in pdf.

Finally, it is very important to underline the commitment shown by all members of GdT5 in this extensive review work, the enriching discussions that took place over the months and the high level of consensus that was reached. This experience has been of great added value and has undoubtedly contributed to strengthening and consolidating the mission of the IIS Partnership as a space and backbone for the life of the IIS.

Development and Results

The Technical Guide for the Evaluation and Accreditation of IIS, as established by Royal Decree 279/2016, is structured around three dimensions: Governance, Strategy, Scientific Capacity and Performance, and Impact on Society. Each dimension is broken down into criteria and sub-criteria to assess compliance with the requirements.

Monitoring the scientific activities and governance of IIS is essential to ensure that they maintain the standards that enabled them to be accredited. It also helps to identify areas for improvement and opportunities for collaboration to strengthen the quality and impact of their research.

To facilitate this monitoring, a system of indicators has been developed based on the sub-criteria of the Guidelines. These indicators form the Monitoring System (CM) of the IIS assessment and accreditation programme. Each IIS must provide regular information on these indicators, which the ISCIII will analyse and return in the form of a status report, contributing significantly to the improvement of the management and scientific strategy of each institute.

As mentioned above, GdT reviewed the 34 annual monitoring indicators dimension by dimension. Following this review, no changes were proposed for a significant part of the indicators. Below are the indicators for which GdT5 proposed changes in each dimension, the reasons for that change and the proposed modification.

DIMENSION 1. GOVERNANCE

Governing bodies/CCE/CCI and Scientific Areas

Percentage of men and women in the governing bodies of the IIS (informative indicators, not dependent on the IIS itself)

This indicator should be informative, as in many cases the gender of the representative does NOT depend on the IIS itself, but rather on the appointment by virtue of the position they hold in the institutions that make up the governing bodies (Governing Council, Board of Trustees, Commission of Delegates). The report they produce after receiving the monitoring system should highlight that gender equality can be achieved in these collegiate bodies.

Reflecting on the appropriateness of disaggregating this indicator is needed, although it would be interesting to request gender data that would allow to establish gender scissor-shaped curves for all levels.

Percentage of men and women in the External Scientific Committee (CCE)

This consultative body of the IIS, whose composition is based on the experience and track record of its members, may not achieve parity and is a body that is rarely renewed. In the short term, it may be more meaningful to monitor the evolution of gender segregation. Including the analysis developed in GT4 (Working Group: Gender Perspective: Strategies for Improvement and Definition of Indicators) is needed.

Percentage of men and women in the Internal Scientific Committee (CCI)

The composition of the CCI is also based on the experience and background of its members, which may not imply parity. It is suggested that it would be more appropriate to monitor the evolution of gender segregation. Incorporating the analysis developed in GT4 is needed.

Percentage of men and women leading scientific areas/programmes

As the leadership of a scientific area/programme is also based on the experience and career of the person concerned, it might be more meaningful to monitor the evolution of gender segregation in the leadership of scientific areas/programmes over time, as in the previous bodies. It is necessary to include the analysis developed in GT4. It would be relevant to extend the indicator to the percentage of female leadership of research groups (R4). They are interrelated. For their harmonised calculation across all institutes, it would be possible to define what is meant by area and/or programme.

Joint and separate management

Financial management

Financial management by the IIS management body.

It is important to clarify the usefulness of this indicator. It is not possible to obtain information on projects managed by the management bodies of the different entities that make up the IIS but are not its core. It would also be necessary to clarify the meaning of the term "funds received".

Support for IIS HR training activities.

Could be extended to IIS capacity building actions in other concepts, not only HR.

It is essential to clarify and/or broaden the concept of "HR training" so that all IIS calculate in the same way and can be comparable.

It is also necessary to clarify the concept of "indirect costs" in order to harmonise it, because it may be different in each IIS (perhaps it can be considered as a singularity).

DIMENSION 2. STRATEGY, CAPABILITY AND SCIENTIFIC PERFORMANCE

2.1 RESOURCES AND PROCESSES. Sheet 1

INFRASTRUCTURES

Infrastructures for research

The IIS has space dedicated to research in at least one primary care centre of the IIS. The management of the use of this space corresponds to the management of the IIS.

Despite the importance of research in primary care (PC) and its contribution to the IIS, this is an indicator that is difficult to comply with due to the management of PC in each Autonomous Community, and therefore the IIS does not have competence in the management of PC or its spaces in most cases. Perhaps it would be more relevant to measure the participation of PC in the IIS with other indicators that estimate staff, scientific production, scientific collaborations, EECC, etc. The current indicator may be meaningless.

Human Resources and Critical Mass

As a general comment on the HR and critical mass indicators, it would be useful to know whether the "disaggregation" by gender is only for information purposes, whether thresholds are set and whether there are consequences for quantification after disaggregation by gender, since in many cases the IIS does not have the capacity to change it (unconstitutionality of recruitment by gender).

Human Resources and Critical Mass

Number of research staff at the IIS who are Principal Investigators (IPs) with active projects funded through competitive public calls for proposals, national from the State Plan or international.

For a harmonious calculation of this indicator among all IIS, it is necessary to define "research project": i) ISCIII and ministry research projects; ii) ISCIII networks, platforms and CIBERs, if the IIS research staff leads and internally manages the IIS participation in the network/platform/CIBER (only 1 IP per network/platform/CIBER IIS is allowed); iii) Miguel Servet, Ramón y Cajal and Juan Rodés contract holders active during the period evaluated; iv) IPs applying for Rio Hortega, Juan de la Cierva, Sara Borrell, PFI and iPFI contracts; v) IPs of infrastructures in national or international public competitive calls; vi) IPs of any EU Framework Programme grant, both as coordinator and as partner, including Marie Curie grants and large initiatives (JPI, JTI, etc.); vii) Leaders at European level of a COST Action; viii) IPs from other European (EU4Healt, Interreg, etc.) and international public programmes (NIH, DoD, etc.).

It is possible to remove the IP concept of competitive RH procurement, but this would perhaps be the subject of a separate indicator, as the ability of the IIS to obtain competitive HR contracts is never measured. Similarly, if the concept of "project" does not include scientific networks, an indicator should be sought to include this information.

It should be specified whether it is intended to include projects obtained by any IP of the IIS (associated clinical research staff) or only by those integrated in groups.

It should be defined what is considered to be an “active” project at the end of the financial year (31/12) Specify whether the start and end dates of the project are taken into account and not the date of award.

This indicator does not include non-competitive or private competitive funding of national relevance, which is not included in other indicators.

Number of research trainees (it corresponds to the R1 profile of the European EURAXESS classification of research profiles).

The EURAXESS definition of R categories should be consistent and harmonised across IIS in order to make the indicator measurable. It is suggested that this categorisation should come from the ISCIII. In addition, it needs to be clarified whether only research staff belonging to groups should be classified or whether associated clinical research staff should also be included. This is a very academic classification that is difficult to apply to a health research institute.

It is important to clarify how this classification affects other indicators.

It is important to mention that the work of GT2 (Working Group “Researcher categories in IIS; classification criteria”) is crucial for this indicator.

Percentage of IPs with healthcare activity that have active projects in competitive public calls for proposals at Spanish, European or international level.

It is important to define “project” in the previous indicators (competitive public projects) in order to define what a IP is. Some highly competitive calls for proposals from the Autonomous Communities or from highly competitive foundations with national concurrence should be taken into account. Defining the figure of a IP with healthcare activity not included in the groups, with great activity in the EECC, may be a singularity.

It is also important to define the threshold, why 40%?

Percentage of IIS researchers who are Primary Care staff.

Review of the relevance and feasibility of this indicator. Clarification on how the threshold was set. Review of its mandatory nature. It may make more sense as an individual indicator, but not as an indicator of excellence in IIS. As mentioned in the previous indicator related to PA, other more appropriate and feasible indicators can be generated to measure cooperation with PA. It is an indicator that should be strengthened, but not “forced”, and it would be more meaningful to monitor its follow-up and evolution, as in the case of the gender indicators.

Percentage of IIS researchers involved in healthcare nursing research.

Definition of health care to harmonise this indicator between IIS: does health care include only “nursing and physiotherapy”? Possibility to include other related diplomas/degrees such as dietetics, speech therapy, podiatry, optometry, midwifery, etc. It could be considered as an indicator of uniqueness rather than a mandatory indicator and could be considered as participation in projects or other research initiatives. It is an indicator that should be strengthened, but not “forced”, and it would be more meaningful to monitor its follow-up and evolution, as in the case of the gender indicators.

2.2 SCIENTIFIC ACTIVITY

Sheet 2 RESOURCE RAISING: Data collection period 2020, except for those in green, which are from 5 years (2016-2020).

Raising resources for research

Number of active projects for which the IIS has obtained funding in national competitive public calls of the State Plan.

This indicator again requires a precise definition of "active project" in the concept (what is considered a project) and in the measurement time (31/12, current year), as indicated in the previous criteria, in order to harmonise between IIS. It is an indicator with a certain cumulative nature, so it could be determined whether it would not be more indicative to collect the annual figure "capacity to attract new funded projects during the year". For the sake of harmonisation, it should be clarified whether the projects of all IP of the institute are counted or only those included in groups.

Percentage of funded projects submitted in response to competitive public funding calls at national level that have been funded.

In order to harmonise between IIS, the same aspects as in the previous section should be clarified. After the necessary clarifications, it is considered a reasonable indicator to estimate the success rate.

Percentage of the annual budget of the IIS corresponding to competitive and non-competitive funding dependent on public funding.

This indicator would need to be redefined in the light of the above comments on project definition, competitive funding and public funding, which in some cases include income/subsidy from the Autonomous Communities and the concept of this subsidy in each one. Gender disaggregation in this indicator may not be appropriate or meaningful depending on the nature of the Autonomous Community subsidy.

It should also be noted that most indicators use the term "funds received", whereas this indicator uses the term "annual project allocation". It should be clarified whether the meaning of this indicator is the same as in other indicators where "funds received" is requested.

Average funding received by IPs (competitive and non-competitive) in the year assessed.

It is recommended to review the usefulness of this indicator and what it is intended to measure. This indicator includes both competitive and non-competitive funding, unlike the immediately preceding indicators which only include competitive funding. Using the mean may be biased; it would be more useful to use the median. Again, this would be an indicator that could be monitored over time (2-3 years), taking into account the periodicity of some competitive calls for proposals.

Active projects funded in European calls obtained by the IIS in the last 5 years.

This is a different indicator from the one proposed in the Evaluation and Accreditation Guide, which includes the number of IPs, and it is therefore proposed to clarify how it should be calculated and the type of grants included (European calls with national funding, such as ERANETs). The defined threshold of excellence is too demanding in terms of European competitiveness. It should also be clarified whether projects active in the last 5 years or projects started in the last 5 years and active at any time during this period should be taken into account. Thus, projects awarded before 5 years but active within these 5 years could be counted.

Projects received from public agencies in other countries (e.g. NIH) should be included as competitive international funding.

Average European funding obtained by each IP in the last 5 years.

Again, the IIS propose to clarify the usefulness of this indicator, given the low funding of some calls that are nevertheless critical and strategic for IPs, groups and IIS (e.g. JPIs such as HDHL). If the IIS leadership is included or calculated in the indicator, it could be considered as a single indicator.

2.2 RESEARCH RESULTS: INDICATORS RELATING TO PUBLICATIONS AND CITATIONS

Sheet 3. BIBLIOMETRY. Data collection period: 1 JANUARY 2018 TO 31 DECEMBER 2019

Research results: Indicators related to scientific production in publications.

For this indicator to be harmonised across IIS, it needs to be clarified: 1) whether the publications of PIs included in IIS groups or also those of associated clinicians are included; 2) whether the publications indexed in the JCR or in the JCR with assigned impact are included (in fact, the recently published JCR includes two new journal indexes, not previously part of the JCR, without assigned impact factor); 3) why only JCR publications are included when there is very relevant and highly cited production from basic disciplines not included in the JCR; 4) whether 'ahead of print' are included.

Normalised Impact Indicator – Normalised Citation Rate (CROWN): number of citations of publications during the analysis period compared to the world average of citations extracted from the BASELINES-CITATION RATES of Essential Science Indicators (Clarivate Analytics) (<http://esi-incites.fecyt.es>) (<https://esi.clarivate.com/BaselineAction.action>)

In general, this is a clear and accepted indicator for the IIS, but some of the following points are worth reflecting on: 1) normalisation should be done at the publication level; 2) it can be highly skewed by a few highly cited publications, so it is suggested to remove the top 1% or top 0.1% publications from the CROWN calculation, although this may further complicate the calculation.

Intra-institute collaboration indicator. Percentage of collaborative publications between IIS groups from at least two different institutions or entities that make up the IIS.

It is proposed to redefine this indicator to quantify collaboration between groups, not only between its member institutions. The level of requirement (40%) is very high considering that there are NO specific calls for collaborative actions of these characteristics. It is proposed to harmonise this indicator with the one required in the Evaluation and Accreditation Guide. In this sense, point 2.3.2.5 of the GTE refers to collaboration between groups from different scientific fields and/or institutions that make up the IIS, but the monitoring system only indicates collaboration between IIS institutions. The criteria should be harmonised.

Global impact indicator. Percentage of IIS publications in the top 10% of the most cited publications in the world in their subject category and year of publication, out of the total number of publications in the same category. Highly Cited Papers 10% (HCP 10%).

A well-defined indicator accepted by IIS, although clarification is requested as to whether publications involving associated clinical research staff should be taken into account.

Visibility indicator. Percentage of publications by IIS researchers published during the evaluation period in which the IIS affiliation is mentioned.

Although the need to strengthen the IIS' affiliation policy is recognised, the value of this indicator is not clearly visualised. It is an indicator that is difficult to use in its current form. Perhaps it should be redefined to include only research staff in groups. What is calculated in this indicator should be standardised across all IIS, or it should be an indicator for internal use in each IIS, without comparison between IIS.

Excellence with Leadership Indicator. Number of IIS publications considered to be excellent (in the top 10% of the most cited publications in the world in their field) that meet the leadership criterion (first, last or corresponding author is an IIS researcher).

A well-defined indicator accepted by IIS, although clarification is requested as to whether publications led by associated clinical research staff should be taken into account.

Leadership Indicator. Percentage of publications with an IIS author as corresponding, first or last author.

A well-defined indicator accepted by IIS, although clarification is requested as to whether publications led by associated clinical research staff should be taken into account. Regarding gender segregation, the definition should include that the relevant position that counts for gender is that of corresponding author. A new wording of the indicator is proposed to facilitate the calculation: the formula should not use the same denominator as the first indicator (column E), but the sum of columns G+H. In this way, the indicator of "publications" by gender would become the indicator of "leading positions" in publications and would add up to 100% reflecting the real number of men and women in leading positions, instead of showing only one in the case of several authors in leading positions.

OPEN SCIENCE. 2020 data

Open Science Policy

Percentage of publications, originals and reviews, in Open Access media in 2020

The Open Access concept must be defined and disseminated, and the collaboration of GT3 is needed. In particular, it is important to define which publication route or licence we should consider as Open Access (gold, hybrid, green and also bronze route). At the moment, it seems that the use of the WOS is the "only" way to achieve reliable exploitation. In particular, the unpaywall database (which uses WoS) allows this analysis to be carried out easily by providing a list of DOIs. If this database were adopted, a small guide on how to use it and perform the calculations could also be included.

Percentage of data resulting from research funded by national and/or internationally competitive public calls deposited in open repositories in the year under review.

There is currently a lack of training and resources in the IIS to address this indicator. The concept of repository needs to be properly defined, as this indicator is currently collected by asking and receiving responses from research staff, information which is not harmonised and not very efficient. At present it is not an accurate indicator due to the lack of knowledge and therefore may be biased and not reflect the reality. It should be removed as mandatory until it is better defined by the IIS. This indicator would also need to define projects that are likely to generate data for repositories and include projects that can and do generate datasets (public or not) that do not relate to humans (viruses, animals, bacteria, etc.).

DIMENSION 3. IMPACT ON SOCIETY. 2020 data, except for those in green, which are from 5 years (2016-2020).

Sheet 1. TRANSLATION AND IMPACT ON THE NHS AND SOCIETY.

Translation into clinical practice

Main actions applied to clinical practice, either in diagnosis or treatment, that were implemented in 2020 as a result of research conducted by the IIS.

There is a need to define specifically what this indicator estimates. There should be a national consensus on how to measure impact and how to prioritise these “quantification ways”. Indications of how the ISCIII interprets the data provided by the IIS are needed. Is the number of actions more important than their impact on society?

Transfer to the productive sector

In general, if an item is not registered or activated in the IIS portfolio, we suggest reviewing its value contribution to innovation and transfer.

Number of intellectual property registrations / know-how licensed, or number of intellectual property registrations licensed, or number of new health products or devices licensed.

The further refinement of the definition of patents —individual, families— is needed. The calculation of start-ups / spin-offs should be reviewed due to the characteristics and legal implications of these creations in the different administrative bodies and in the different Autonomous Communities. It should be noted that some IIS do not have specific OTRIs and use those of some of their constituent institutions. This information is already collected for indicators and CM of MICIN, so it would be advisable to unify the requests from different national bodies. Regarding the possible inclusion of clinical practice guidelines in this indicator, it should be clarified whether only those published in academic journals can be included.

Percentage of funds raised by products transferred to the productive sector out of the total annual funding of the IIS.

This indicator is currently difficult to calculate as it is necessary to define what is meant by “products transferred to the productive sector”. The numerator and denominator need to be clarified. In addition, it should not be compared between IIS, as it can be very different depending on the orientation of the IIS. It could perhaps be considered as a singularity indicator rather than a mandatory indicator. The returns may not go to the governing body of the IIS, but to the governing body of some of its constituent institutions. Again, this information is already provided to other ministerial and regional bodies; it is recommended that this information be unified and communicated between them in order to facilitate the work of the IIS.

Sheet 2. SCIENTIFIC COMMUNICATION AND PUBLIC PARTICIPATION

Scientific communication and public participation

Commissions involving non-scientific actors

This is an indicator that the IIS considers to be meaningless. The definition of “non-scientific actors” should be improved, and it is not the number of commissions that should be assessed, but the purpose of the commissions that may make it relevant to include a “non-scientific actor”. It is important to assess the contribution of these actors to each commission, in terms of their nature and content, before including them in the commissions. Perhaps the figure of the “Social Council” could be proposed as a single commission that includes these actors in an advisory role.

Dissemination activities carried out by the IIS aimed at citizens of target groups.

It is necessary to redefine the indicator, with the following important aspects to be taken into account: specifying what is considered as a dissemination activity, specifying categories of specific activities, homogenising indicators for publications in social networks, news on the web, conferences, events, etc., and assessing whether the IIS have the necessary resources and tools to measure it. This, as well as other RRI indicators, still needs a lot of development and implementation in the IIS before it can be included in the CM.

It is important to note that some of the proposals for changes to the indicators made by GdT5 in 2021 have already been reflected and included in the 2023 and 2024 CM.

Considerations And Recommendations Of The Working Group On Indicators Of The Monitoring System

After analysing the current CM indicators, the Working Group agreed on the following considerations and recommendations:

1. Simplification and focus: To reduce the number of CM indicators to those that are essential for assessing the scientific activity and transfer of results of the IIS.
2. Harmonisation and comparability: To homogenise the CM indicators to allow equivalent analysis of IIS responses and to provide an accurate picture of the overall activity of all accredited IIS.
3. Uniformity and Consensus: To align the CM indicators with those of the IIS Evaluation and Accreditation Guide (GTE) to measure the same concepts in a consistent manner.
4. Caution when including novel indicators: To defer the inclusion of indicators related to concepts that are still under development and not widely implemented in IIS (Open Access and Impact). Two illustrative examples of this recommendation are given: in the case of Open Science, the difficulty of the datasets indicator should be addressed. For new indicators in the Impact dimension, international experts should be consulted and new indicators should be communicated at least one year in advance.
5. Review of Excellence Thresholds: To adjust the thresholds of excellence based on the retrospective assessment of the last 3 years of the IIS.
6. Efficiency in data collection: To centralise the request for transmission indicators required by several institutions to a single body or ensure that all request the same indicators.
7. To contrast the analysis of CM indicators carried out by the GdT5 with the retrospective evaluation carried out by ISCIII: To compare the current review of CM indicators with the retrospective assessment of CM in all IIS carried out by the ISCIII. To reach a consensus and harmonise the considerations.
8. New revisions of the indicators: If the current revisions are considered constructive for CM by the ISCIII, the IIS are ready to present detailed proposals for the modification of the indicators, in a dynamic and sustained process over time.
9. Periodic review and update of the CM: Support the continuity of a process of review and updating of the CM and the GTE, with the participation of the IIS, in order to adapt the indicators to the evolution of scientific activity in the progress of the IIS over time.

Finally, it must be emphasised that all IIS highly appreciate the opportunity to participate in the activities to review the evaluation criteria, which they firmly believe will contribute to the generation of more useful and realistic information for a much more efficient management of IIS and the achievement of scientific excellence and impact on society and patients.

Health Research Institutes Internationalisation

GT1. *Institute Partnership*. 2022.

Coordination: IIS INCLIVA

Manager: Dr. Andrés Cervantes. General Director of IIS INCLIVA.

Executive Summary

In mid-2022, the ISCIII, through the General Sub-Directorate of Research in Cell Therapy and Regenerative Medicine, proposes the creation of a Health Research Institutes Partnership. The objectives are: a) to create a stable space for cooperation and joint work between the ISCIII and the accredited IIS in order to respond to the needs of the IIS in the dynamic environment of R&D&I; b) to align the scientific policies of the IIS with the strategic lines of the European framework; c) to promote cooperation between the IIS, creating synergies that increase their competitiveness; and d) to promote the participation of the IIS in the definition of the ISCIII's lines of action.

In order to achieve these objectives, the ISCIII has set up various working groups, including the Internationalisation Working Group, led by IIS INCLIVA and with the participation of 10 other IIS. Its specific objectives are: a) To identify strengths in aspects such as: scientific areas with greater leadership. Mapping of resources/capacities and b) Creation of a virtual platform/repository to facilitate the coordination of the interests of the IIS, with the aim of greater competitiveness and leadership of Spanish participation in European actions.

The **methodology** used for the preparation of this report consists of the definition of a set of indicators, the consensual elaboration of a form between the 11 IIS of the GdT and the ISCIII, and the standardised collection and subsequent analysis of information from the 34 accredited IIS.

The results of the standardised analysis show that:

- The project management role is the most recurrent, followed by the financial justification role.
- The funding obtained varies between IIS from a maximum of €46.6 million to a minimum of €0.63 million, for a total of €248.6 million, with a concentration of 45% in Catalonia, followed by 24% in Madrid, 9% in Andalusia, 6% in Valencia and Navarra and 5% in Galicia.
- The most successful fields in terms of number of proposals and projects are 1st oncology, 2nd metabolism, 3rd cardiovascular, 4th neurosciences and 5th infectious diseases, inflammation and vaccines.
- The most used resources by research lines with European projects are the cell culture and biobank unit, closely followed by the phase 1 clinical trials unit, biostatistics and bioinformatics platforms and big data and artificial intelligence platforms.
- The research lines with the highest participation in proposals are 1st Translational Medical Oncology, 2nd Neurosciences, 3rd Metabolic Diseases, 4th Microbiology, 5th Others, followed by Translational Cardiology. The lines with the highest number of projects are 1st Translational medical oncology, 2nd Microbiology, 3rd Neurosciences, 4th Genetics, vaccines, infections and paediatrics, 5th Metabolic diseases.
- The research lines with the most coordinated projects are 1st Translational Oncology, 2nd Neurosciences, 3rd Metabolic Diseases, 4th Neurological Impairment, 5th Genetics. The lines with the most projects

as beneficiary entity are: 1st Translational Oncology, 2nd Microbiology, 3rd Neurosciences, 4th Metabolic Diseases, 5th Genetics.

- The lines of research with the most funding are: 1st Medical oncology; 2nd Microbiology; 3rd Neurosciences; 4th Metabolic diseases; 5th Genetics, vaccines and infections.
- The research lines with the greatest capacity for coordination and leadership are: 1st “Other” (selected by the IIS if they cannot find a corresponding research line), followed by 2nd Microbiology, 3rd Medical oncology, 4th Clinical cardiology, 5th Psychiatry and neurodegenerative diseases and 6th Neurosciences.

Introduction

This report arises from the need to have a map of the strengths and capacities present in health research institutes in relation to participation in international projects, mainly Horizon 2020 and Horizon Europe (2014 to date). To this end, a number of indicators have been analysed, resulting in a ranking of the areas and lines of research with the highest return capacity.

In this detailed analysis, we also asked about the expectations that each IIS would have of a virtual platform/repository that would facilitate the coordination of the interests of the IIS, aimed at greater competitiveness and leadership of Spanish participation in European actions.

Theoretical Framework

The theoretical framework used in this report analyses the strategic axes of Spanish and European programmes and initiatives for the period 2021-2027.

In order to see the alignment of the IIS with these strategic axes, the research programmes of the European Union (HE, IHI, EU4HEALTH) as well as the Spanish Strategy for Science, Technology and Innovation (EECTI) ², the National Strategy for Artificial Intelligence (ENIA) ³, the Spanish Strategy for R&D&I in Artificial Intelligence ⁴ and the Strategic Action in Health (AES) ⁵ have been analysed.

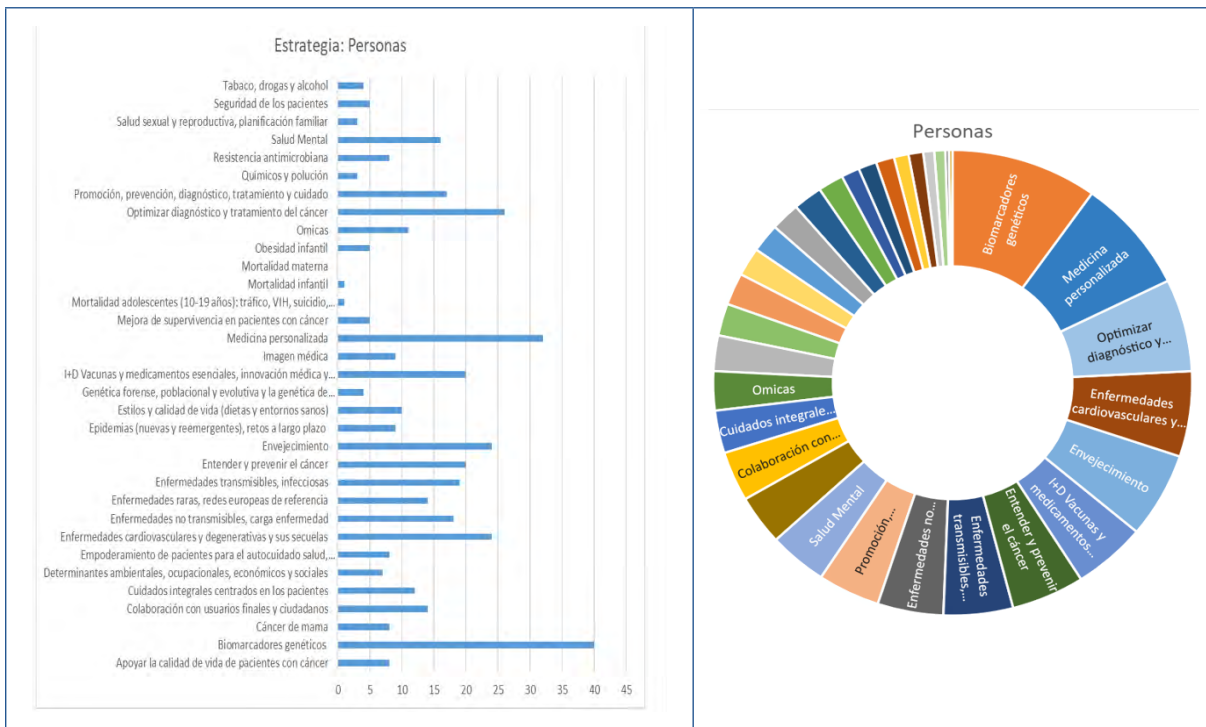
The People indicator covers the range of policies aimed at improving people's health. The Technologies indicator covers the main areas of technology focused on health. The Health Systems indicator covers those aspects aimed at improving the health system itself. Finally, the Types of projects indicator refers to the type of research project.

2 <https://www.ciencia.gob.es/stfls/MICINN/Ministerio/FICHEROS/EECTI-2021-2027.pdf>

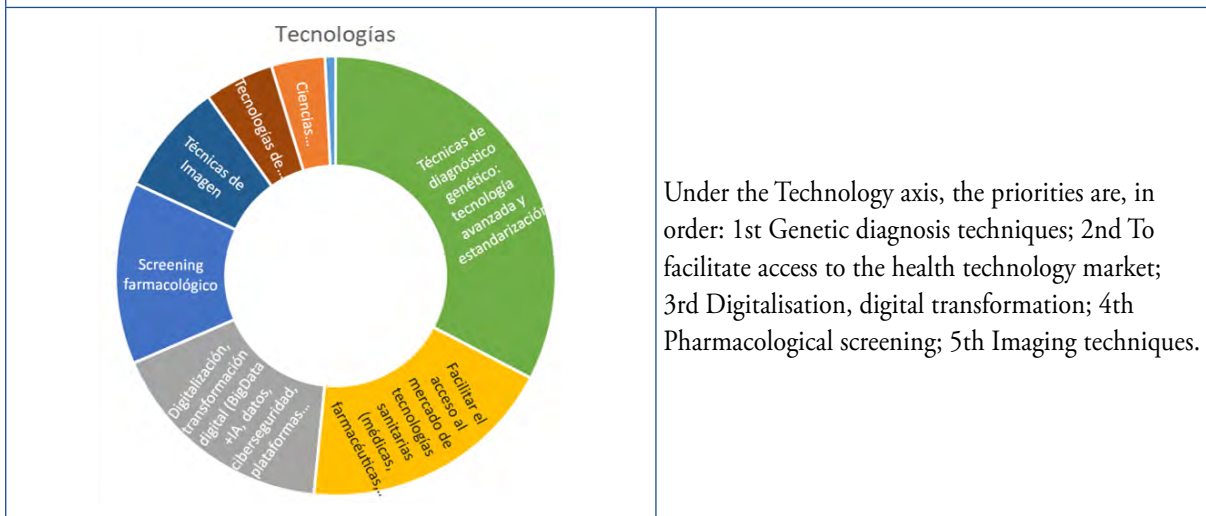
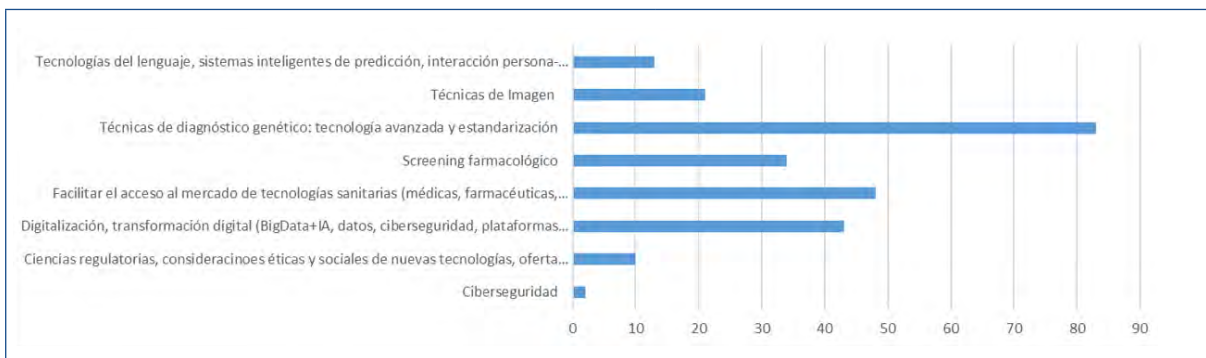
3 https://portal.mineco.gob.es/RecursosNoticia/mineco/prensa/noticias/2020/201202_np_eniav.pdf

4 https://www.ciencia.gob.es/stfls/MICINN/Ciencia/Ficheros/Estrategia_Inteligencia_Artificial_IDI.pdf

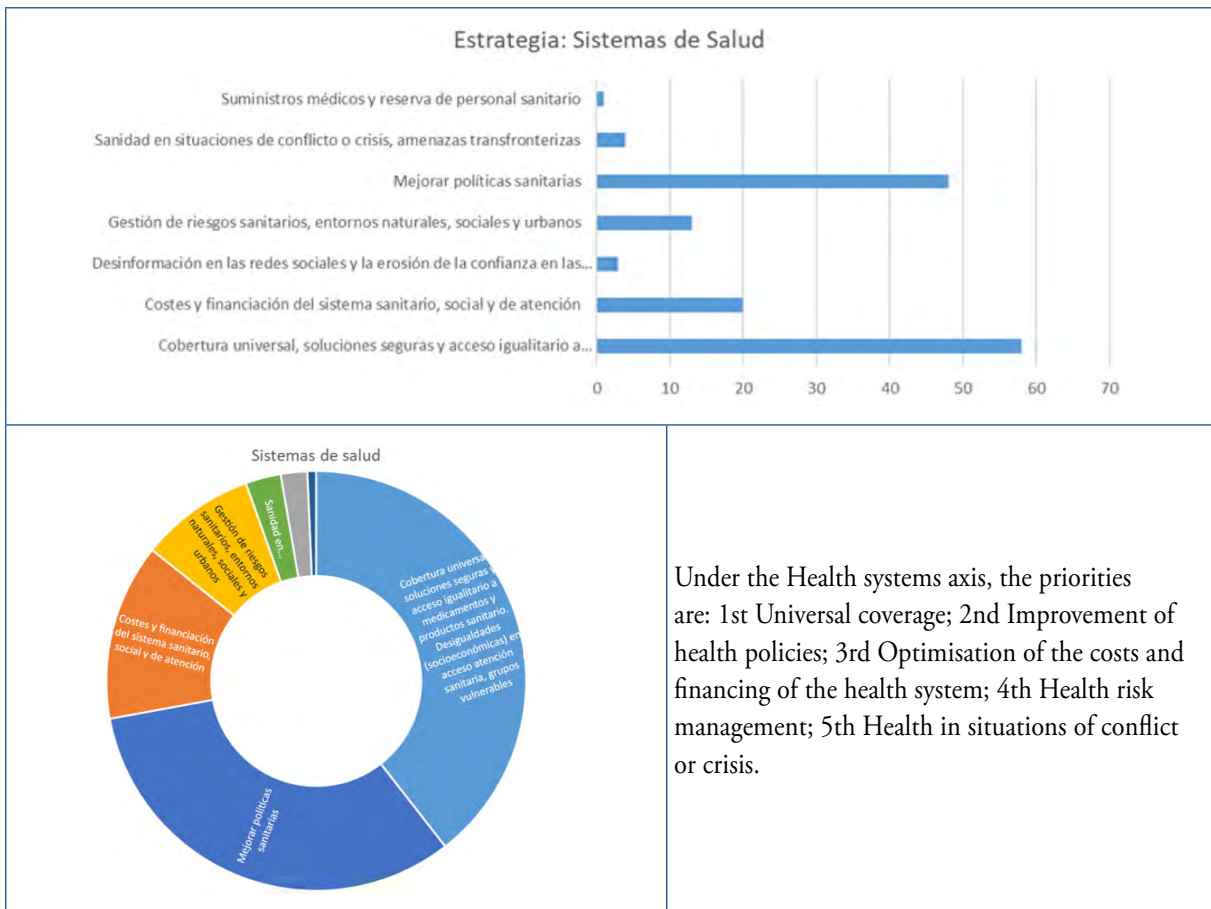
5 <https://www.ISCIII.es/QueHacemos/Financiacion/Paginas/AccionEstrategica-en-Salud.aspx>



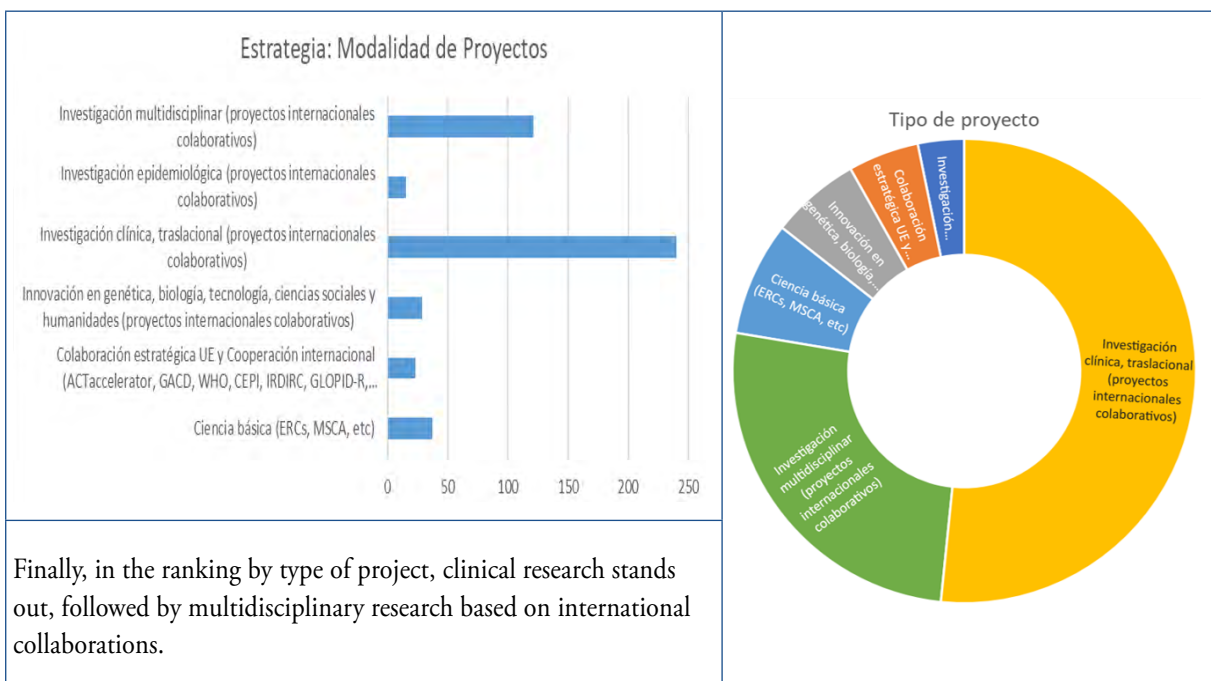
Under the People axis, the following strategies stand out: 1st genetic biomarkers; 2nd personalised medicine; 3rd optimisation of cancer diagnosis and treatment; 4th cardiovascular and degenerative diseases; 5th ageing.



Under the Technology axis, the priorities are, in order: 1st Genetic diagnosis techniques; 2nd To facilitate access to the health technology market; 3rd Digitalisation, digital transformation; 4th Pharmacological screening; 5th Imaging techniques.



Under the Health systems axis, the priorities are: 1st Universal coverage; 2nd Improvement of health policies; 3rd Optimisation of the costs and financing of the health system; 4th Health risk management; 5th Health in situations of conflict or crisis.



Finally, in the ranking by type of project, clinical research stands out, followed by multidisciplinary research based on international collaborations.

Methodology

The methodology used to produce this report was divided into three phases:

- 1st Definition by the Internationalisation Working Group (11 IIS) of the indicators to be collected and preparation of the form/survey.
 - The 11 IIS involved were: INCLIVA (COORDINACION), IdISSC, IIS BIOCRUCES, IMIM, IRB LLEIDA, IDIS, IMIBIC, IDIPHIM, IRYCIS, IGTP and IMIB.
 - Several meetings were held to discuss the names/themes of the global areas and lines of research that would best summarise the research activities of the different institutes. Once the IIS involved in GT1 have agreed and defined the indicators, the form is drawn up and then validated with the ISCIII.
- 2nd Sending of the form to the 34 IIS and compilation of the individualised information.
- 3rd Analysis and aggregation of the results for the preparation of this report.

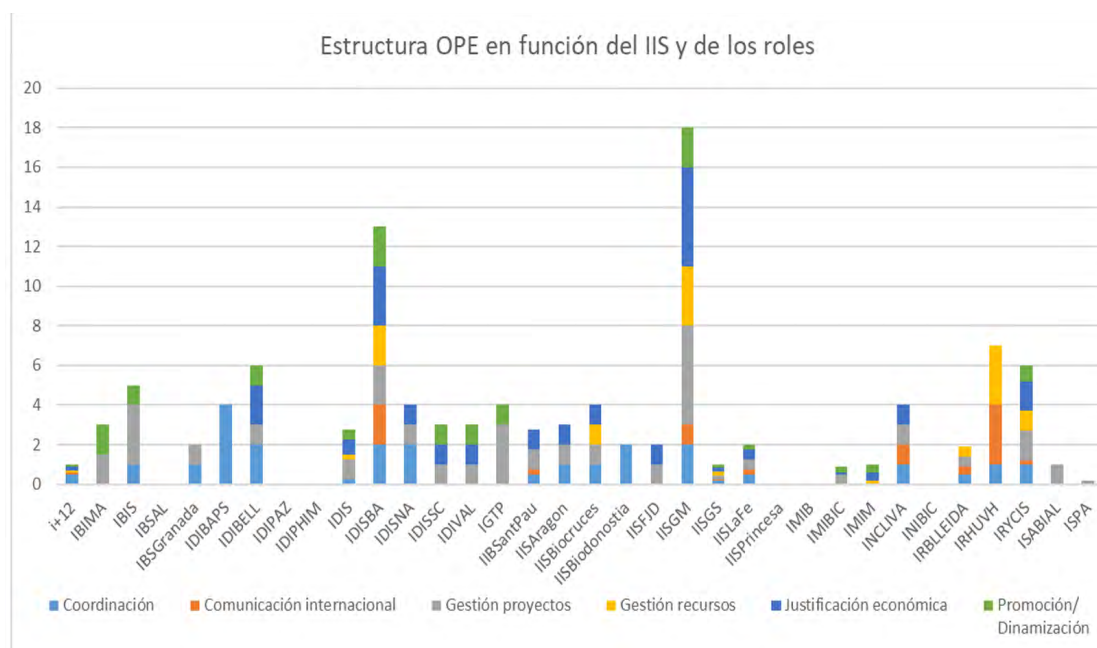
Development and results

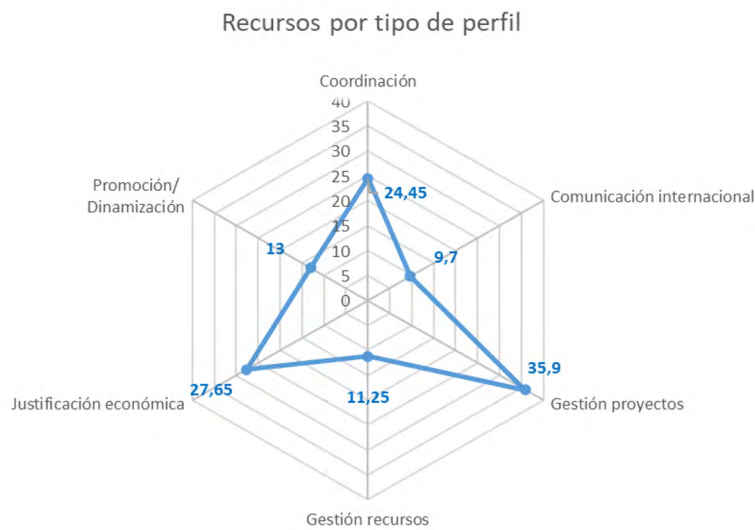
Strengths in scientific areas with a greater leadership. Mapping of resources/capacities

Structure of international project units.

This indicator shows the number of people in each IIS who perform the following 6 roles: coordination, project management, resource management, economic justification, dynamization/promotion and international communication. Out of a total of 34 IIS, 29 (82%) responded to this indicator and 5 (18%) did not respond.

IDIBAPS, IDIBELL, IDISNA, IDISBA and IISBiodonostia indicate that they have more than one person in charge of coordination. Beyond this clarification, it is interesting to note the existence of all roles in almost all IIS. Clearly, the project management role is the most recurrent, followed by the financial justification role. This is followed, with almost equal weight, by the role of promoting and stimulating participation in new calls for proposals and the role of managing resources in funded projects.

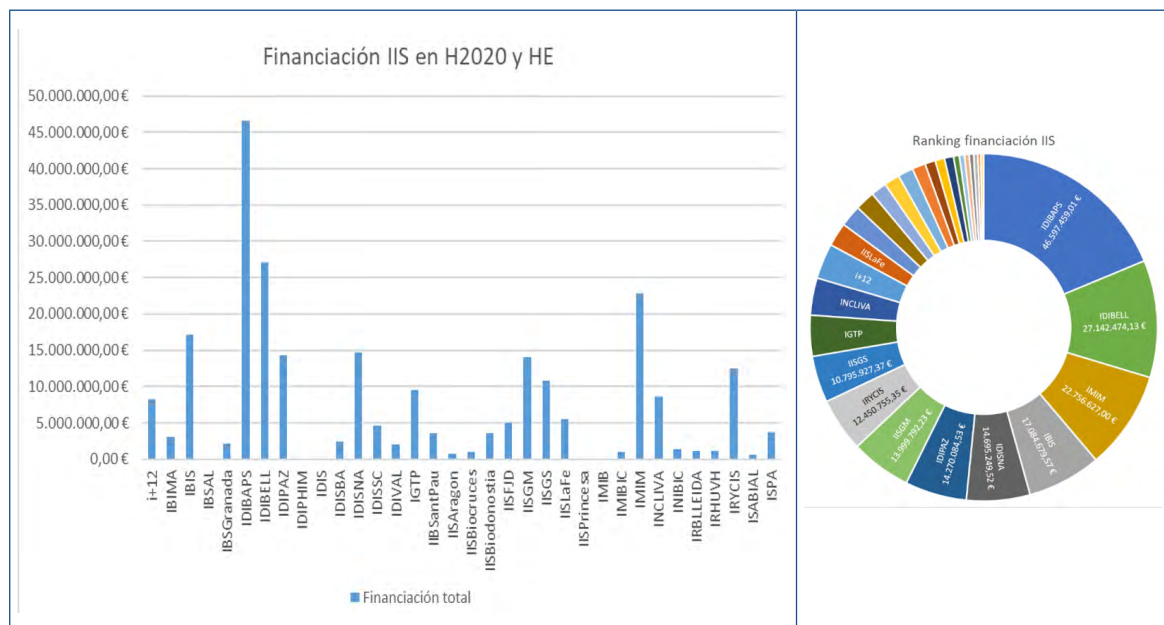




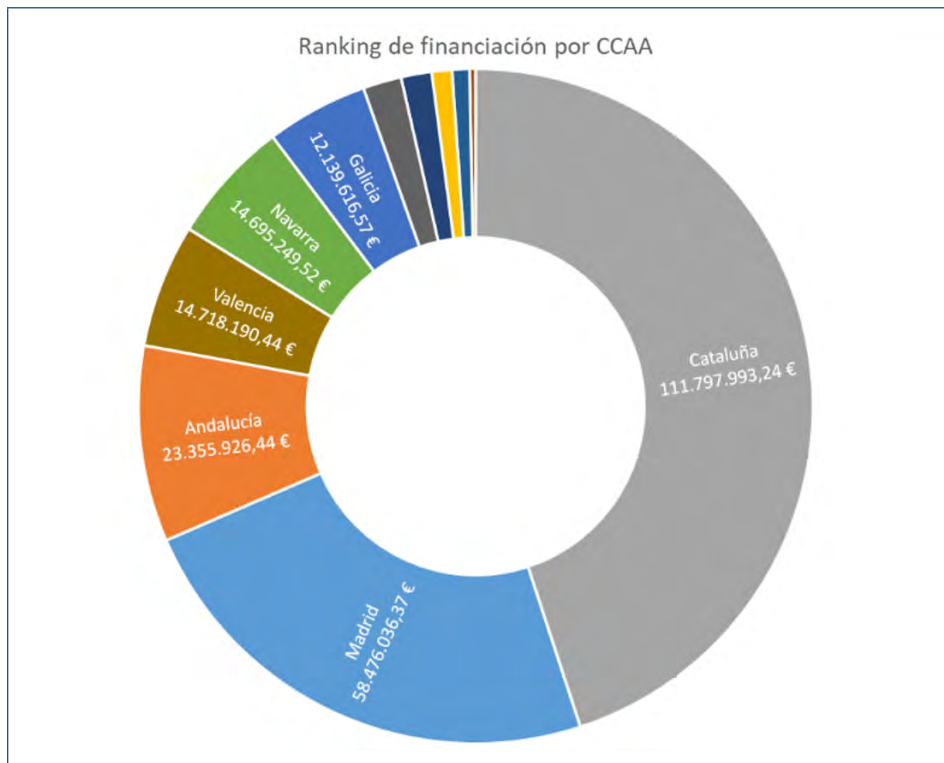
Cumulative return in H2020 and HE. Geographical distribution

This indicator shows the funding received by each IIS, mainly in the Horizon 2020 and Horizon Europe programmes, from 2014 to the present.

This funding received by the IIS varies between a maximum of 46.6 M€ for IDIBAPS and a minimum of 0.63 M€ for ISABIAL. In the first quartile of funding are IDIBAPS, IDIBELL, IMIM, IBIS, IDISNA, IDIPAZ, IISGM and IRYCIS.



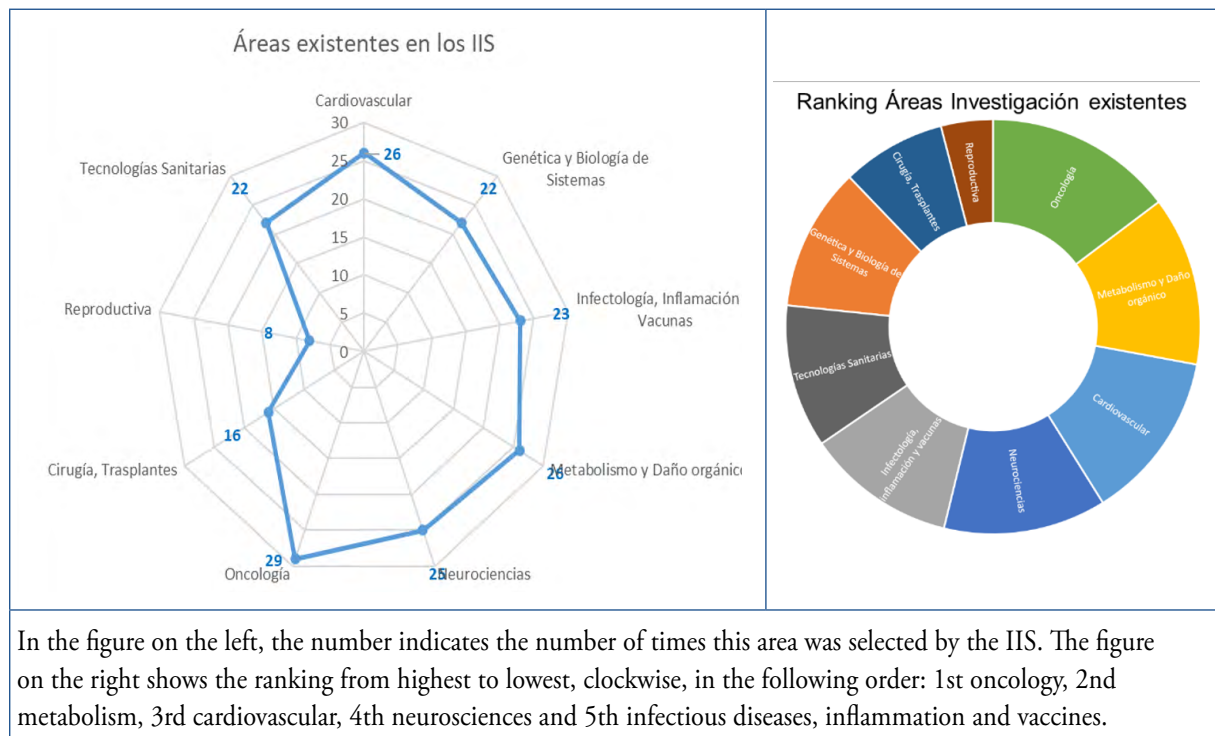
The total funding resulting from the sum of the amounts of the 29 IIS that replied amounts to €248.6 million. The distribution of this funding by Autonomous Community shows a concentration of 45% in Catalonia, followed by 24% in Madrid, 9% in Andalusia, 6% in Valencia and Navarre and 5% in Galicia. The remaining percentage is distributed between the Balearic Islands, Cantabria, the Basque Country and Asturias. The Autonomous Communities of Castilla y León, Aragón and Murcia did not provide any data, and they are under-represented in this distribution.



Research areas with international proposals and projects

This indicator shows those research areas within the IIS that have participated in funded European projects and/or European calls for proposals, even if the participation was not successful.

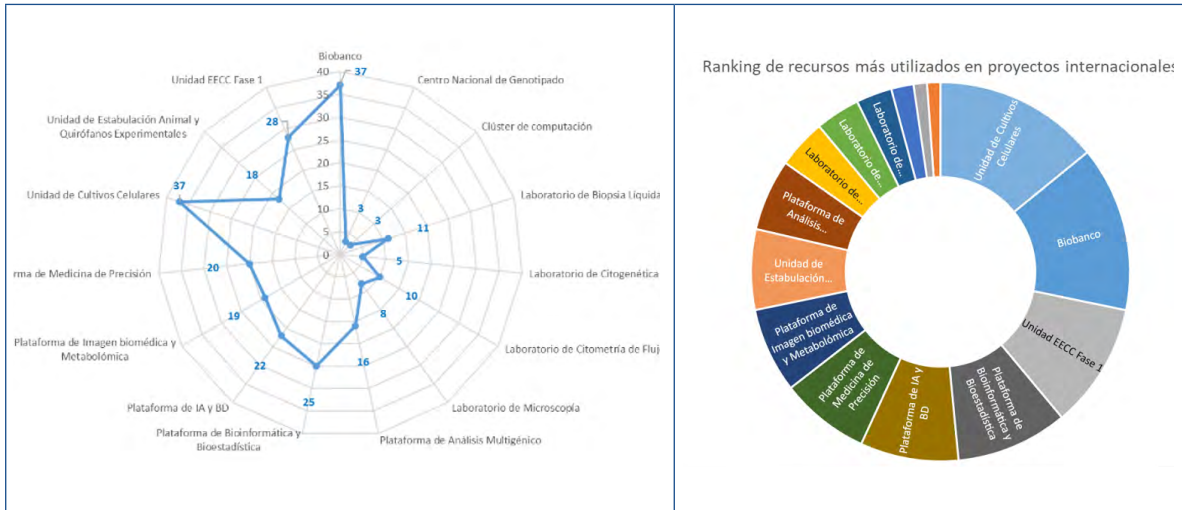
Out of a total of 34 IIS, 30 (88%) responded to this indicator and 4 (12%) did not respond.



In the figure on the left, the number indicates the number of times this area was selected by the IIS. The figure on the right shows the ranking from highest to lowest, clockwise, in the following order: 1st oncology, 2nd metabolism, 3rd cardiovascular, 4th neurosciences and 5th infectious diseases, inflammation and vaccines.

Resources most used by lines of research with European projects

This indicator shows the resource that each line of research defines as most relevant for research in European proposals and/or projects. Out of a total of 34 IIS, 28 (82.3%) responded and 6 (17.6%) did not respond.

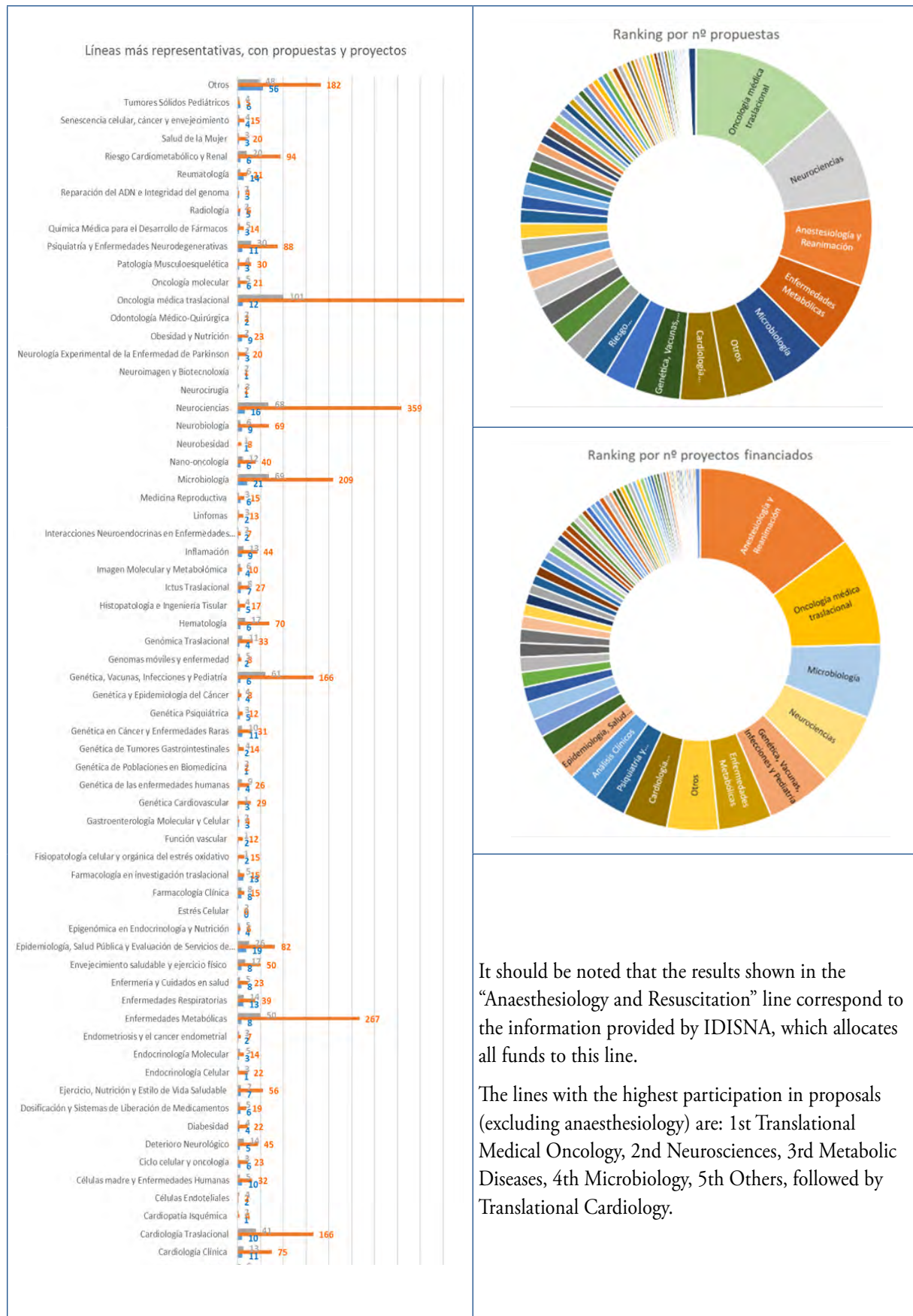


The radial graph on the left shows the number of times the resources were selected, while the projection on the right shows the ranking of these resources, from highest to lowest, clockwise. The first two positions are occupied with equal weight by the cell culture and biobank unit, closely followed by the phase 1 clinical trials unit, biostatistics and bioinformatics platforms and big data and artificial intelligence platforms.

Results obtained in H2020 and HE

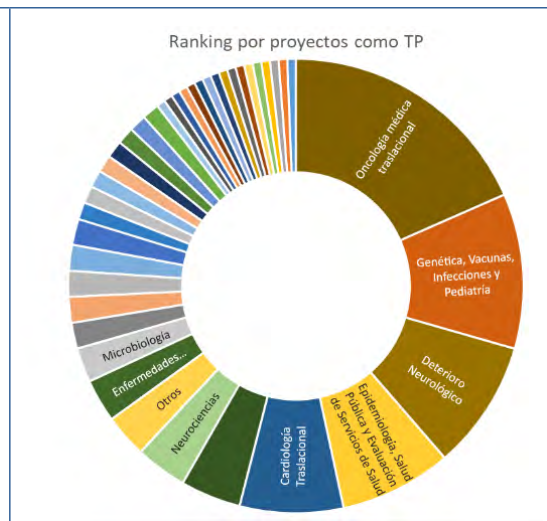
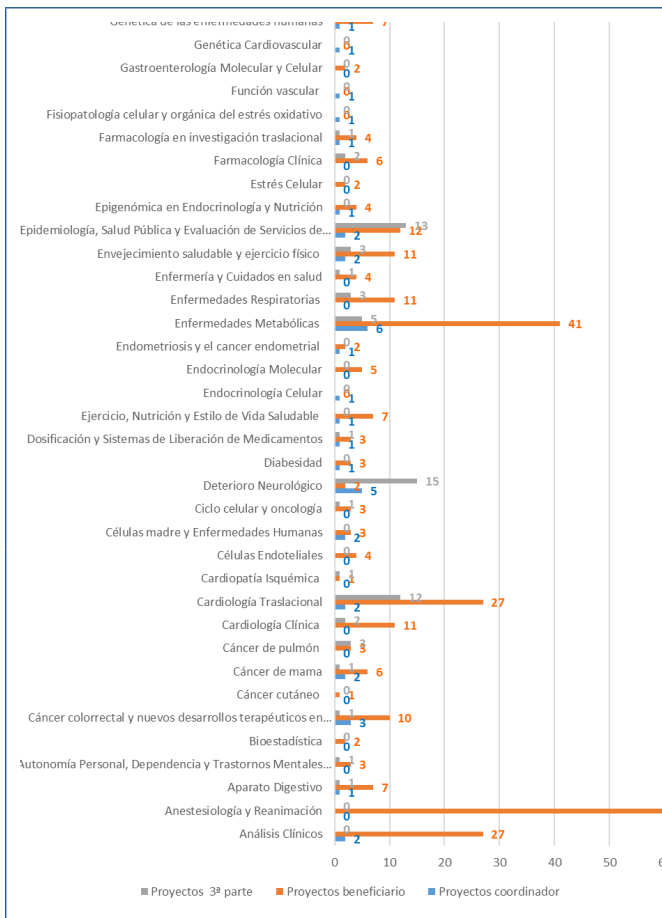
- Ranking of proposals and projects by line of research

This indicator shows, in combined form, those lines of research for which at least one international project has been awarded and for which total funding of more than €100K has been indicated. The category “Other” should be taken into account, which corresponds to the selection made by the IIS when they do not find a line related to those indicated in the form.



It should be noted that the results shown in the “Anaesthesiology and Resuscitation” line correspond to the information provided by IDISNA, which allocates all funds to this line.

The lines with the highest participation in proposals (excluding anaesthesiology) are: 1st Translational Medical Oncology, 2nd Neurosciences, 3rd Metabolic Diseases, 4th Microbiology, 5th Others, followed by Translational Cardiology.

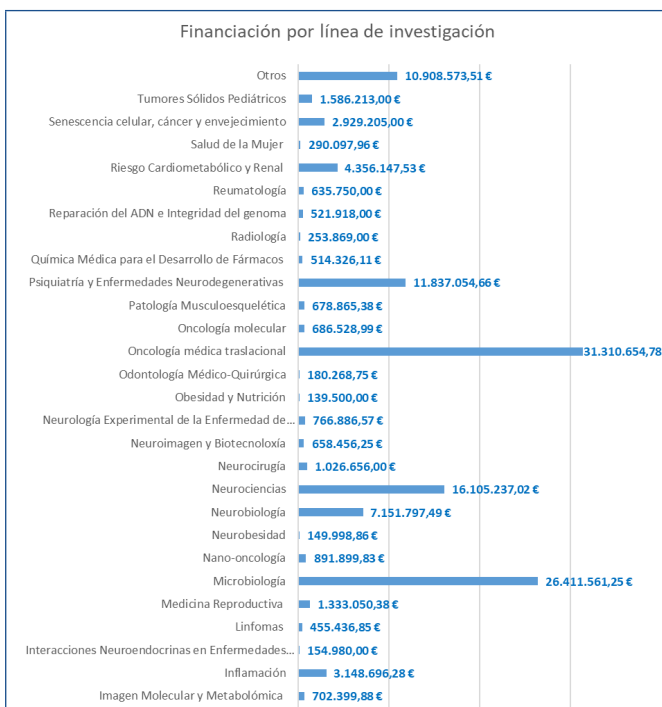


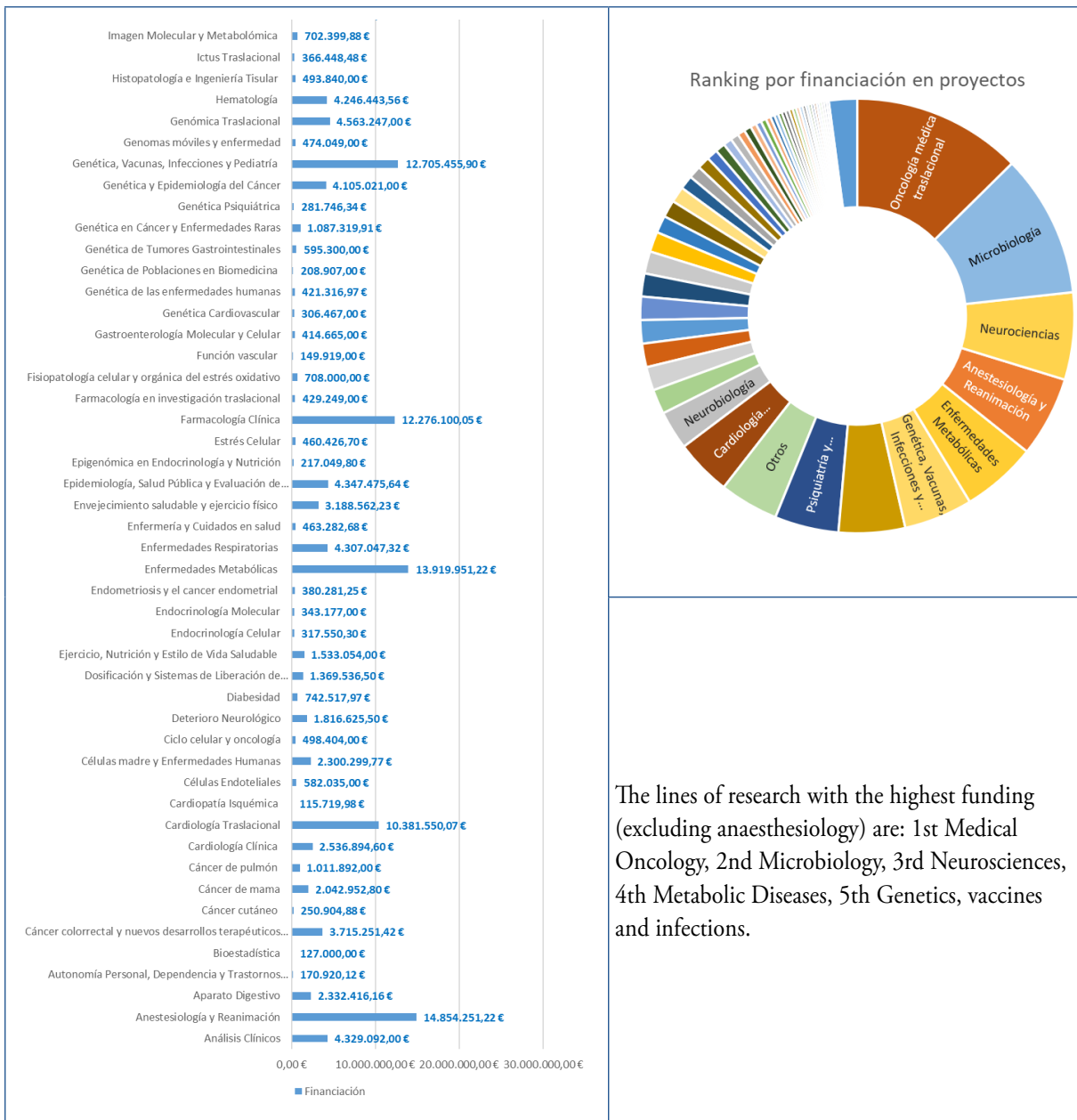
The lines with the most coordinated projects are: 1st Translational Oncology, 2nd Neurosciences, 3rd Metabolic Diseases, 4th Neurological Impairment, 5th Genetics.

The lines with the most projects as beneficiary entity (excluding anaesthesiology) are: 1st Translational Oncology, 2nd Microbiology, 3rd Neurosciences, 4th Metabolic Diseases, 5th Genetics.

• Ranking of lines of research by funding received

This indicator shows the funding (>100.000€) received by each line of research and the ranking, counter-clockwise, from highest to lowest.



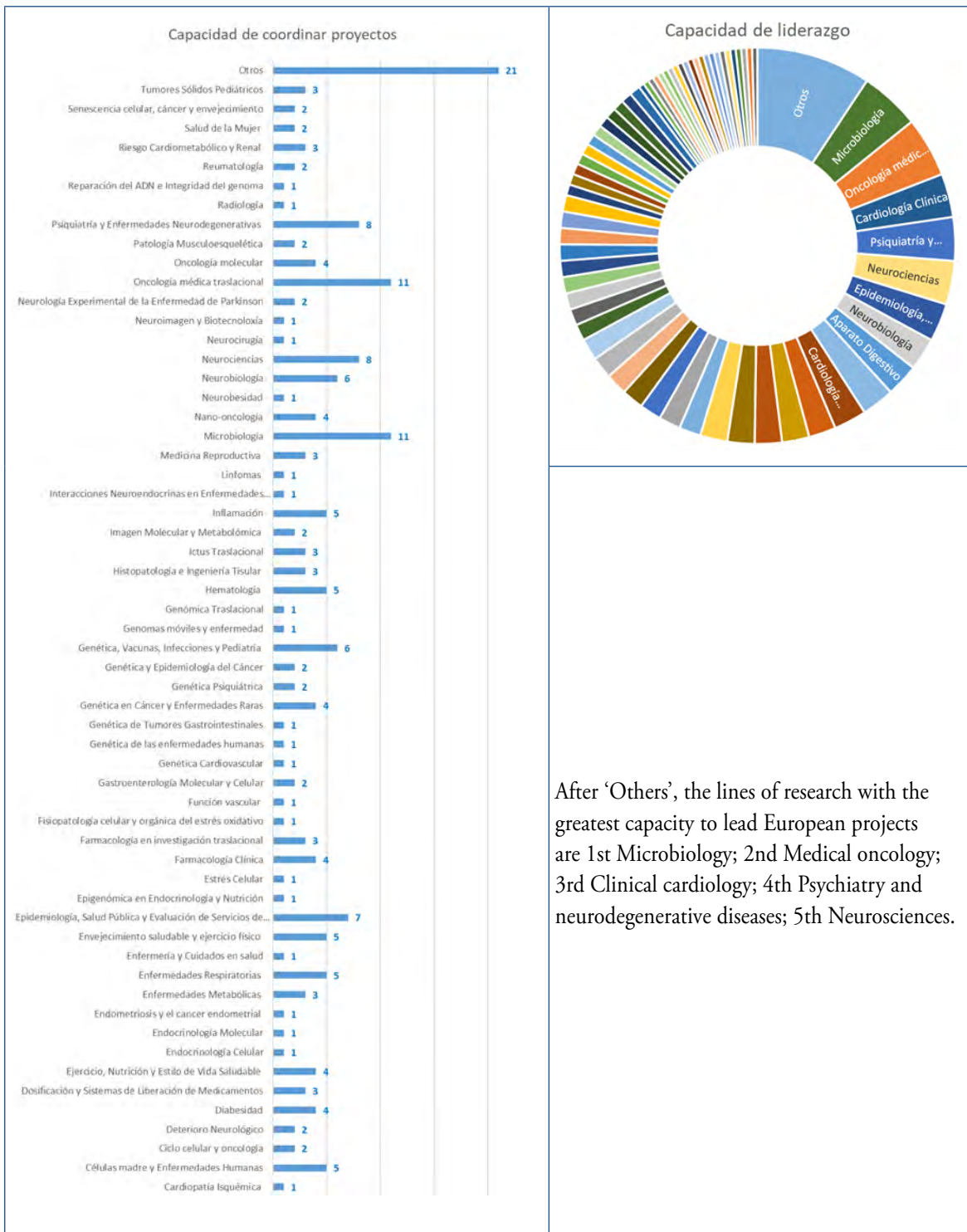


The lines of research with the highest funding (excluding anaesthesiology) are: 1st Medical Oncology, 2nd Microbiology, 3rd Neurosciences, 4th Metabolic Diseases, 5th Genetics, vaccines and infections.

• *Ranking of lines of research by coordination and management capacity*

This indicator shows the project management capacity of each research line. Only those selected at least once by an IIS are shown.

The selection “Other” (the most representative in this indicator) represents the selection made by the IIS when they do not find a relevant line of research.



Conclusions and Suggestions

Virtual platform/repository

This section summarises the expectations expressed by the IIS when asked about the creation of a virtual platform or repository to facilitate the coordination of the interests of the IIS, aimed at greater competitiveness and leadership of Spanish participation in European actions.

Of the 34 IIS, 21 (62%) replied to this question and 13 (38%; IBSAL, IDIPHIM, IDIPAZ, IDISBA, IDIVAL, IISPrincesa, IMIB, IMIBIC, IMIM, IRBLLEIDA, IRHUVH) did not reply. Responses are shown in the right column.

IIS	What do you need from a common platform/repository for all IIS? (Free text answer). Additional comments
i+12	<p>Platform/repository requirements:</p> <p>To have a data design and structure that serves its purpose, validated by IIS; validated data; direct loading from databases such as cordis to reduce manual loading (from PIC, etc.); easily accessible data by several managers of the same centre; tools to identify future partners (entities/individual researchers); descriptors of (entities/individual researchers): proposals, calls, collaborations, profiles (similar to EEN marketplace but adapted).</p>
IBIMA	<ul style="list-style-type: none"> – To be able to deposit the publications and research results of the IIS in open access, in order to comply with national and European policies in this respect. – Training in data management and the preparation of the corresponding plans as required by national/European calls. – To improve the synergies between the IIS to participate in European/international calls.
IBIS	<p>Following the premises of the Open Access movement, a repository should be a source of specialised, organised and accessible digital information. A tool for storing, preserving, disseminating and providing open access, being a key collaborative tool between the IIS; providing shared resources, patents and collaborative studies, ...</p>
Ibs.Granada	<p>Of the 22 proposals granted, 7 were from non-EU competitive calls (US or UK origin). One MSCA-ITN call is included.</p> <p>Definition of minimum resources and/or capacities (scientific and managerial) to start the internationalisation process. Nothing is included about the difficulties of the IIS to apply for international projects through the managing units, if we are talking about the university or other units that make up the IIS (payroll issue).</p> <p>It is necessary to ensure that repository data are standardised. With regard to the expectations that each IIS has of a virtual platform/repository that would facilitate the coordination of the interests of the IIS, aimed at greater competitiveness and leadership of Spanish participation in European actions, no joint analysis is made, nor is anything proposed. We propose to include recommendations to the ISCIII, based on the information analysed. There are no conclusions or recommendations.</p>
IDIBAPS	<ol style="list-style-type: none"> 1. To identify entities that can cover the priorities of the Horizon Europe framework programme where it is more difficult to find real experts. 2. To create an agile system for finding experts for consortia. <p>The following actions are proposed in order to promote the participation of IIS in Horizon Europe calls, strengthen the attraction of talent and increase the international visibility of the institutes:</p>

	<p>1. Each IIS should have a contact person who can easily identify the skills and the research group within the institute that can meet the needs being sought. 2. To attach the list of units that make up each graph in sections “2.5.2. Ranking of lines of research by projects as coordinator”, “2.5.3. Ranking of research lines by funding received” and “2.5.4. Ranking of research lines by coordination and management capacity”. 3. To strengthen the dissemination of the IIS network as a whole and improve its brand image.</p>
IDIBAPS	<p>The creation of a platform that comprehensively summarises the activities of the IIS would require a significant investment in human resources. In addition, there are already platforms that provide useful information on the funding of each entity, or with expressions of interest for collaboration (e.g. Funding and Tenders Portal). However, it would be useful to facilitate collaboration between IIS given i) the heterogeneity of profiles currently required by collaborative projects, ii) the difficulty in accessing certain experts (e.g. policy-making, ethics), iii) the need to identify experts of recognised prestige, iv) the need to include patients from multiple centres in clinical trials. It is proposed to create: 1. A platform to disseminate among IIS the specific needs to be addressed in the collaborative projects under development. 2. An alert system integrated into this platform to streamline the flow of information between IIS.</p>
IDIBELL	<ul style="list-style-type: none"> – Partner search support – Training for managers
IDIS	<p>An ISCIII platform available to all IIS could be useful for coordinating the submission of proposals to international calls. Among the functions that this platform could perform are facilitating the search for partners, promoting the participation of IIS in large consortia, providing support for specific proposals, acting as a national contact point, etc.</p> <p>By knowing the main research strengths of each IIS, the platform could facilitate the flow of information and thus the inclusion of IIS in certain consortia in order to increase their participation in international projects.</p>
IDISNA	<p>It is needed to facilitate the compliance with the ethical and legal requirements that we need to consider before we can deposit health information in publicly accessible repositories. In addition, it would be appreciated if we could be provided with data governance plans after deposit in the repository, taking into account that the organisations that have received the information are responsible for the proper management and re-use of the data.</p>
IDISSC	<p>A platform that would allow agile and direct communication with other IIS, enabling rapid contact to form consortia depending on the needs of the proposal.</p>
IGTP	<p>A platform with OPE contacts to facilitate the formation of consortia.</p>
IIB SantPau	<ul style="list-style-type: none"> – A database of potential partners to form consortia, depending on the research area or type of proposal.
IIS Aragon	<ul style="list-style-type: none"> – To unify common criteria for all

	Information on draft calls before they are published. Information on the formation of consortia. Better practices in project management.
IIS Biocruces	A first test could be interesting by selecting a limited number for each IIS, for example 5 scientific areas with the highest leadership and 5 resources/capacities. To start, it could be with a simpler management dimension, which could be expanded later, depending on operability.
IIS Biodonostia	<p>The IIS Biodonostia is scientifically structured around seven vertical research areas: Neurosciences, Liver and Gastrointestinal Diseases, Infectious Diseases, Oncology, Epidemiology and Public Health, Bioengineering and Systemic Diseases. It also has three cross-cutting research areas: Ageing, Precision Medicine and Innovation. On the other hand, it has platforms such as: Animal Facility and Operating Room, Biobank, Bioinformatics, Genomics, Cell Cultures, Histology, Molecular Diagnostics, 3D Printing and Clinical Research. Finally, it has a number of R&D&I support units/services, staffed by qualified personnel for the development of the Institute's management activities. Scientific areas with the greatest leadership: Neurosciences Area, Liver and Gastrointestinal Diseases Area, Oncology Area and Bioengineering Area.</p> <p>We believe that it would be very useful if the platform could provide some of the following services: – Specialised training in proposal writing. – Training in the administrative and financial management of projects. – A platform to support the search for partners and the formation of consortia. – A repository of relevant documentation on European projects. – A monitoring system allowing quick access to open calls for proposals. – Handbook of good practices for European projects. – Examples of success stories.</p>
IISFJD	(In the right columns, I have listed the applications and projects granted according to the actual research areas and groups at the IIS-FJD.° Some of these are already reflected in some way in the drop-down menus, others, such as Pathological Anatomy, are not).
IISGM	<p>Indicators not sufficiently defined. Indicators of different interpretation by IIS, data not comparable. In the IISGM, we have not taken into account the percentage of staff employed and, in addition, depending on the person, they may be counted for more than one activity and therefore be counted more than once in the overall calculation of the IIS. The high degree of heterogeneity in the definition of topics, areas, etc. results in a large number of small groups which make interpretation difficult. We suggest grouping them into larger thematic areas.</p> <p>Constitution of an IIS lobby to achieve objectives such as simplifying participation in European calls and improving our results in Europe. Creation of a platform to identify calls and potential partners.</p>
IISGS	A platform that undertakes coordination actions for the realisation of actions such as: a) Presentation and preparation of proposals with the participation of several IIS. b) Identification, at national level, of IIS that could be suitable partners in proposals that come to this platform.
IIS LaFe	<ul style="list-style-type: none"> – Accredited training resources that professionalise the figure of the project manager. – Training resources specialised in the internationalisation of biomedical research.

INCLIVA	<ul style="list-style-type: none">– Possibility to collaborate as affiliated entities.– Possibility to include patients in clinical trials or pilot tests/conceptualisation/scale-up in European projects.– Joint training resources– Joint accreditation of OPEs management staff
INIBIC	<p>A repository with an alert system to identify possible candidates for inclusion in the project.</p> <p>An alert system for all health technology assessment units in other communities.</p> <p>A platform to identify different laboratory techniques for the training of professionals in the centres.</p> <p>A platform to indicate the new materials being tested in the different research centres.</p> <p>A platform for new vaccines based on phages or strains of phages that are considered at risk in different hospitals, in order to be able to generate therapies to combat them.</p> <p>A platform to identify, through an alert system, which pathologies are being tackled by a common therapeutic target.</p> <p>A platform to know the state of the art of vaccines in each centre, as well as their level of development and optimisation.</p> <p>A platform integrating all possible virus variants with the capacity to cause an epidemiological problem.</p> <p>A platform for sharing new chemicals with health risks.</p> <p>A platform with interoperability capacity to manage patient data for application to other patients with different disease profiles.</p>
IRYCIS	<p>* To facilitate the search for partners and/or companies to promote the participation of IIS in large consortia.</p> <p>* A platform to provide relevant documentation according to the strategies defined by the CE for the preparation of proposals.</p> <p>* Platform for the ISCIII to inform the IIS about the CE funding policies in the different calls where the ISCIII act as NCPs.</p>
ISABIAL	<p>Possibility of cooperation between the different IIS in order to increase the ratio of projects applied for and received.</p> <p>Join training for the different managers.</p> <p>A rapid communication channel between the IIS.</p>
ISPA	<p>Ability to search for partners</p> <p>Specialised training for managers</p>

IIS recommendations

As a summary of the above table, the following is a list of overlapping recommendations made by several IIS for the creation of a common platform/repository:

- A platform that facilitates the search for partners and thematic experts and the formation of consortia and the communication/participation of several IIS in the same project, being able to act as affiliated entities of each other in the area of clinical trials, proof of concept, pilots, scale-up, etc.
- A platform to enable joint specialised training and accreditation of both international project management professionals and researchers for the internationalisation of biomedical research.
- A platform that acts as an alert system and brings together all relevant information and documentation on calls for proposals (from the first draft stages), events, courses, European strategies, funding policies, etc., as well as manuals on good practices and common criteria in European projects with examples of success stories.
- An open access platform that facilitates compliance with ethical and legal requirements for the deposit of publicly accessible health information, becoming a repository of specialised, organised and accessible digital information. A tool for storing, preserving, disseminating and providing open access, being a key collaborative tool between the IIS; providing shared resources, patients, collaborative studies, ...

There are also other IIS proposals that deserve to be highlighted because of their relevance:

- A platform that can provide specific support for certain large proposals and act as a national contact point and lobbying structure.
- A platform to facilitate the identification of novel capabilities of IIS (laboratory techniques, new materials, new vaccines, virus variants, health risk chemicals, etc.).

Data Management Plan

GT2. *Institute Partnership*. 2022.

Coordination: IIS ARAGON

Manager: Dr. Ángel Lanás. Scientific Director of IIS ARAGON.

Executive Summary

This report is the result of collaboration between ten health research institutes (IIS) within the IIS Partnership, with the aim of developing a guide for the preparation of data management plans (DMPs) in research projects, following international standards and complying with current regulations. The document addresses three key areas: tools for the preparation of DMPs, resources needed for proper data management, and training needs in the IIS for the proper implementation of such plans.

DMPs are essential in research projects as they allow for efficient, ethical and compliant management of the information collected, ensuring data accessibility and re-use during and after the project. Proper data management ensures the quality and integrity of information, promotes transparency and reproducibility, and facilitates scientific collaboration. It also highlights the importance of aligning DMPs with FAIR (Findable, Accessible, Interoperable, Reusable) principles, promoting open access to data and extending their impact through re-use by other researchers and sectors.

The report also analyses existing tools for creating DMPs, assessing their ease of use, collaborative features, adaptability to different disciplines and ability to manage data budgets. It also reviews recommended repositories and platforms for storing and sharing health research data, both nationally and internationally, and suggests that researchers use existing repositories rather than creating new ones.

Finally, the training needs of IIS are identified, highlighting the importance of training researchers and managers in the proper development and use of DMPs. This includes training on ethical aspects, technological tools, and data storage and preservation. It is suggested that this training be coordinated by the Institute of Health Carlos III (ISCIII) and that the creation of professional profiles specialised in data management be promoted to support researchers.

The report concludes with recommendations on the use of free software tools, the centralisation of efforts in existing repositories, the promotion of specialised profiles in data management and the need to train all actors involved in research projects to ensure the correct implementation of DMPs and compliance with data protection and intellectual property regulations.

Introduction

Data play a central role in research projects as they are the basis on which knowledge is generated, hypotheses are tested and conclusions are drawn. In this context, data management plans (DMPs) are essential to ensure that the information collected is managed efficiently, consistently and ethically. A data management plan in a research project is a strategic tool that helps to organise how data are collected, stored, documented, shared and preserved to ensure that they are accessible and reusable not only during the research but also in the future.

The importance of these plans lies in several key aspects. First, they ensure the integrity and quality of the data, which is essential for the validity of the results. Proper data management avoids errors and loss of

information and ensures that collection and analysis methods are replicable, increasing the transparency and reproducibility of research. In addition, in an environment where scientific collaboration is increasingly common, DMPs make data understandable and accessible to other researchers, thereby promoting knowledge sharing and the generation of new ideas.

An increasingly important aspect of DMP is the promotion of open access to data in line with the FAIR (Findable, Accessible, Interoperable, Reusable) strategy. The FAIR philosophy encourages data to be easy to find, openly accessible, compatible between different systems and reusable for future studies. This strategy not only improves the transparency and reproducibility of results, but also increases the impact of research, as open data can be used by other researchers and sectors, accelerating scientific progress. Including open data management in a DMP also aligns projects with the policies of many funding agencies, which increasingly require that data generated by publicly funded research be openly accessible.

Another key factor is regulatory compliance. In many disciplines, particularly in the health sciences, where personal data is particularly sensitive, there are strict regulations on how data must be handled. DMPs help researchers to comply with these regulations, protect the privacy of research subjects, and avoid legal sanctions. In addition, many funding agencies and scientific journals require projects to have a data management plan to ensure that research results are accessible and verifiable.

Finally, a data management plan contributes to the sustainability of the project. By ensuring that data are stored securely and properly documented, their long-term preservation is facilitated, allowing research results to remain relevant and useful for future research. In summary, a DMP not only ensures more efficient and rigorous research, but also increases confidence in the results, promotes long-term scientific innovation and contributes to more open and accessible science for all.

Theoretical Framework

Data Management Plans (DMPs) are fundamental to modern scientific research as they ensure the proper and ethical management of data. This section presents the main conceptual and normative frameworks that underpin the need for and relevance of DMPs.

Data lifecycle

The data lifecycle describes the stages that data go through in a research project, from collection to preservation and re-use. A DMP guides this process to guarantee that the data is managed consistently and efficiently at each stage, ensuring its quality and future accessibility.

International and national standards

DMPs must comply with regulations such as the General Data Protection Regulation (GDPR), which governs the handling of sensitive personal data, particularly in areas such as biomedical research. Funding agencies also require projects to meet ethical and regulatory standards for data management.

FAIR Principles

The FAIR (Findable, Accessible, Interoperable, Reusable) strategy is central to the DMP. These principles ensure that data are:

- Findable: through proper documentation and the use of metadata.
- Accessible: through open access policies where possible.

- Interoperable: compatible with different systems and tools.
- Reusable: well documented for use by other researchers.

Open Science and Data Access

Open access and open science aim to democratise scientific knowledge by making data available for re-use. DMPs facilitate this access, which improves reproducibility and multiplies the impact of publicly funded research.

Benefits of efficient management

A well-implemented DMP will ensure:

- Improved data quality: ensuring accuracy and verifiability.
- The fostering of scientific collaboration: making data easier to understand and reuse.
- Regulatory compliance: minimise legal risks and ensure compliance.

Training and skills

The development of DMP requires that researchers and data managers receive specific training in data protection, ethics and the use of technological tools. Institutions such as the Institute of Health Carlos III (ISCI) promote continuous training to ensure competence in research data management.

Methodology

In order to achieve the proposed objectives of the working group, 3 different sub-groups were set up, each focusing on one objective.

In the first one, “To produce a guide for researchers to prepare data management plans in accordance with international recommendations for good practice and in compliance with current regulations”, 6 tools to assist in the preparation of data management plans were assessed. The selection of the tools was made on the basis of the experience of the members of the working group with them, as well as the accessibility of their use. All the tools are regularly used by European research organisations, although some of them have a national scope.

In order to make the comparison homogeneous, it was agreed to carry out a qualitative assessment by setting the following criteria for all of them:

- Free
- Opensource
- It accepts templates that meet the requirements of different funders
- It allows new templates to be uploaded
- It automatically completes fields
- Exportable formats
- Usability of the tool
- Collaborative: several people can work at the same time

- Learning curve
- Languages
- Ability to deposit data
- Ability to work with DMP versions
- Adaptability to the health sector
- Ability to incorporate data management budget

In parallel, the second sub-group has focused on the objective of analysing the resources required to adequately undertake data management in the IIS. The work carried out focused on the selection of repositories most closely related to the areas of health research. Once these had been mapped by the working group, an individual analysis of 3 international repositories was carried out. The search for repositories revealed that most of them were included in data platforms, which were also analysed. The platforms analysed were RECOLECTA and ELIXIR. Both are institutional, the former promoted by the FECYT and the latter by the European network ELIXIR. At the end of the analysis, conclusions were drawn on the use of the repositories and the usefulness of the platforms. An analysis was also made of the different professional profiles that could be involved in the data management process. The different members of the working group shared their experiences and defined both the qualifications and the complementary training that they should have.

Finally, the last sub-group identified the training needs for the implementation of data management plans, for which a survey was carried out in the field of IIS.

Development and results

With regard to the tools for producing data management plans, the analysis is presented for each of the 6 selected tools and for all the criteria mentioned above.

DMP Online
Free
Yes
Opensource:
Yes
It accepts templates that meet the requirements of different funders (e. g.: Horizon Europe)
The tool allows the funder entity to be identified and the template provided by the funder to be used (e.g. European Research Council or European Commission). However, if the funder is not in the list or there is no funder associated with the DMP, a template will be created based on the “DCC Template” provided by the Digital Curation Centre according to their own guidelines: Checklist for a Data Management Plan. v.4.0. Edinburgh: Digital Curation Centre. Link: http://www.dcc.ac.uk/resources/data-management-plans
It allows new templates to be uploaded
No. The templates available are uploaded by the Digital Curation Centre (DCC) and are not updated on Horizon Europe.

It automatically completes fields

It allows the auto-completion of fields structured in different sections. In the case of the generic “DCC Template”, these are: 1) Data Collection; 2) Documentation and Metadata; 3) Ethics and Legal Compliance; 4) Storage and Backup; 5) Selection and Preservation; 6) Data Sharing; 7) Responsibilities and Resources. In the case of the “Horizon 2020 DMP” template provided by the European Commission, it is also possible to produce different versions of the DMP depending on the current status of the project: Initial DMP, Detailed DMP and Final Review DMP.

Exportable formats

The formats that can be exported are: csv, html, pdf, text, docx, json. It also allows the font format in pdf and 3 additional download options:

- Unanswered questions
- The text of the questions and sections
- Project details sheet

Usability of the tool

Easy to read and download, simple functions and menus, comfortable to use, it contains guidance on each of the sections that make up the DMP.

Collaborative: several people can work at the same time

It allows the addition of those who will contribute to the elaboration of the DMP. Name, email, ORCID, affiliation and role in the DMP are requested for each. Roles include: Data Manager, Principal Investigator, Project Manager and Other.

Learning curve

Quick and intuitive learning curve. You can review public plans in your field, calls for proposals or peers in the institution/university.

Languages

Spanish, English (UK or US), French, German.

Ability to deposit data

It is not a data repository.

Ability to work with DMP versions

DMPonline allows you to create copies of the same DMP. For each version or copy, you can invite collaborators and specify whether they are invited to read or edit the plan. Invitees are notified by email that they have access to the DMP. It is also possible to configure the visibility of the plan, with at least 50% of the questions to be answered to enable “Public” and “Organisational” visibility.

Adaptability to the health sector

Lack of specificity on key issues such as ethical and legal issues. However, easily adaptable through other templates that have these sections (e.g. the standard DCC template).

Ability to incorporate data management budget

Generally no, but there are templates that include this (data management costs as in the template Data Management Plan (September 2020) from the Netherlands Organisation for Scientific Research (NWO)).

DSW: Data Stewardship Wizard

Website

<https://ds-wizard.org/>

Description

Open source tool developed by ELIXIR to facilitate the creation of a data management plan based on what are (currently) considered “good practices”.

Price

The tool is free, although there is a commercial option (“FAIRWizard” for “Groups and Institutions”, which is probably what an institution with the ISCIII would need).

Open source

It is open source and configurable.

Templates

It allows the use of templates from different funders (<https://ds-wizard.org/document-templates>).

It allows the development of new templates

It automatically completes fields

This is one of the strong points of the tool. Not only does it allow you to autocomplete fields, but it also has several question systems for helping.

Exportable formats

It does not have, or I have not been able to find, a DMP export option. It does allow you to export your knowledge model in JSON format and administrators can migrate to another knowledge model. If by “export” it means how to generate the DMP document, this can be done in Word, Latex or PDF.

Usability of the tool

The tool has several aids throughout the process to facilitate its use.
It seems to be powerful in this respect.

Collaboration

It is possible to share a project once it has been created, so that people with access can work on it simultaneously.

Languages

The tool is in English and it is not immediately clear whether other languages can be used.

Learning curve

The fact that there is a lot of help available at all stages of the process, as mentioned above, makes the learning curve easier. There is a lot of courses and workshops on its website.

Ability to deposit data

It does not appear to have this capability.

Ability to work with DMP versions

Version control is included and it is possible to access to a history of versions and changes made.

Adaptability to the health sector

It is a general tool with no templates or specific indications for health projects.

Ability to incorporate data management budget

It has a “Storage Cost Evaluator” that generates an indicative estimate of storage costs based on the amount of information and the time it will be stored.

References

<https://datascience.codata.org/articles/10.5334/dsj-2019-059/>

EasyDMP

Free

Free to all researchers accessing from Europe and Norway. Free access from <https://easydmp.sigma2.no>

Opensource

Free software under the MIT licence, which allows you to use, modify and redistribute the software. Source code available for download.

It accepts templates that meet the requirements of different funders

When a new DMP is created, the template to be used is selected. Currently it has defined: Science Direct y EU Horizon 2020 template.

It allows new templates to be uploaded

The help guide gives the possibility to define new templates by contacting the developers. However, the fact that it is free software allows you to create your own installation containing templates adapted to the needs of your institution.

It automatically completes fields

Not available.

Exportable formats

Acrobat Reader pdf and html formats.

Usability of the tool

Very simple. The questions defined in the template appear in sequential order, making it easy to complete.

Collaborative: several people can work at the same time

It allows the definition of co-editors who will receive a link allowing them to edit the DMP.

Learning curve

Short. It is very easy to use, as it does not have many options and focuses on the sequential completion of predefined information.

Languages

English only.

Ability to deposit data

Not available directly from the tool.

Ability to work with DMP versions

Not available.

Adaptability to the health sector

No specific adaptation.

Ability to incorporate data management budget

Not available.

EINA.DMP (CORA)

Free

Yes

Opensource

Yes (DMPRoadmap).

It accepts templates that meet the requirements of different funders

Yes, there are templates for Horizon Europe, H2020, ERC, State Plan and others that are not specific to a particular funding agency. There is also a Software Management Plan template and a simplified template for PhD students.

It allows new templates to be uploaded

Yes, templates can be generated on an ongoing basis. If an institution/s has its own template(s), these templates can also be uploaded.

It automatically completes fields

Yes, but limited in number.

Exportable formats

Pdf, docx, html, csv.

Usability of the tool

Easy.

Collaborative: several people can work at the same time

Yes, anyone can register and use the tool.

If an institution has created a space within Eina.dmp, the visualisation is limited in some fields for users from outside the institution. In addition, permissions can be given as co-owner (all permissions), collaborator (add, comment but not share) or read (view only).

Learning curve

Quick and intuitive learning curve.

Language

English.

Ability to deposit data

Yes, it has its own CORA repository which requires separate registration. This is another independent tool and in the coming months it will present additional functionalities that will allow “communication” between it and Eina.dmp.

Ability to work with DMP versions

Yes, different versions of the history can be created and retrieved.

Adaptability to the health sector

No, for example, there are no extended functionalities/fields on relevant issues such as security or ethics in the use of sensitive data.

Ability to incorporate data management budget

Yes, although the tool does not allow the uploading of files (e.g. Excel). There is a specific section where budget information can be included in a narrative form.

PGDOnline

Description

Web tool developed by the Consorcio Madroño to create data management plans, adapted from DMPonline by the DCC (Digital Curation Centre UK).

Website

<https://pgd.consorciomadrono.es/>

Free

Yes, but it currently only includes the Universities of the Community of Madrid as institutions.

Opensource

Yes

It accepts templates that meet the requirements of different funders

No, it currently only works with the Horizon 2020 template

It allows new templates to be uploaded

No

It automatically completes fields

No. Fields must be completed manually. The tool only guides you on which fields to complete and provide a description of what is required in each section.

Exportable formats

csv, html, pdf, texto, doc.

Usability of the tool

The tool is very intuitive. It does not require any previous learning.

Collaborative: several people can work at the same time

Yes. Collaborators and different levels of visibility of the plan can be added.

Learning curve

Easy.

Languages

German, English, Spanish, French, Portuguese. Translation at template level.

Ability to deposit data

No.

Ability to work with DMP versions

No. It is only possible to define an initial plan, a detailed plan and a final plan. In each phase, the number of questions to be answered increases.

Adaptability to the health sector

No, it is a generic DMP generation tool.

Ability to incorporate data management budget

Argos

Description

It is an online tool for the creation, management, dissemination and linking of a DMP that emphasises the application of FAIR principles and best practices to promote the accessibility of research data. It is open and collaborative, and has been developed jointly by OpenAIRE.

Website

(<https://www.openaire.eu/>) and EUDAT (<https://www.eudat.eu/>).

Free

Yes, and Argos does not require a specific registration, as it allows you to log in by selecting one of the providers on the login page (OpenAIRE, ORCID, EUDAT, GMAIL or via social network profiles such as Facebook or Twitter).

Opensource

Yes, <https://argos.openaire.eu/opensource-licences>

It accepts templates that meet the requirements of different funders

Yes. It provides most of the templates needed to access research funding, as well as the one needed to apply for Horizon Europe funding.

It allows new templates to be uploaded

Yes, but with an administrator account. With an administrator account, it is possible to propose new templates tailored to the needs of authors and funding agencies. The administrator account must be requested from argos@openaire.eu

It automatically completes fields

Yes. The template allows interoperability with other Openaire tools. Argos allows the automatic completion of data when a resource has already been loaded into one of these tools or repositories. During the process, dialogue boxes appear to facilitate the autocompletion task.

Exportable formats

DMP can be exported in both machine-understandable formats (xml, json) and human-understandable formats. Specifically: PDF, document, XML, RDA JSON (can be imported into other RDA compliant DMP tools).

Usability of the tool

- Setup assistant for creating the DMP according to the funder.
- Setup assistant for describing the research data so that it can be reused in different DMPs.
- Assignment of a DOI to the DMP if it is published, facilitating the visibility and citation of the DMP itself.
- DMP can be exported in both machine-understandable formats (xml, json) and human-understandable formats.
- Service included in the European Open Science Cloud (EOSC), an initiative supported by the European Commission.
- It is linked to the user's ZENODO account. In this way, it links the data management plans to the datasets deposited in ZENODO, the multidisciplinary repository created by the European Union to comply with the general open data project.
- There is no size limit for either the plans or the datasets.

Collaboration

Yes. The DMPs generated in ARGOS are in turn managed as research products to which DOI, licences, etc. can be assigned. It also allows DMPs to be made collaboratively by several people.

Learning curve

Throughout the autocompletion process, dialogue boxes will appear to help the researcher to complete the data management plan according to the practical guidance provided in each of the fields. This allows the researcher to gain an overview of data management in the context of the project, while building skills for future data management plans.

Languages

9 languages including Spanish.

Ability to deposit data

Yes. It is linked to the user's ZENODO account. In this way, it links the data management plans to the datasets deposited in ZENODO, the multidisciplinary repository created by the European Union to comply with the general open data project.

Ability to work with DMP versions

Yes, it also allows downloading in different formats, inviting researchers to work in groups, and uploading new versions.

Adaptability to the health sector

No. However, the questionnaire or template contains fields to fill in and to answer some of the specific keys derived from data processing in the health sector, such as: informed consent, anonymisation, data processing, allocation of roles in processing, and ethical issues.

Ability to incorporate data management budget.

The template includes questions related to the allocation and management of data management costs, but does not include a specific tool for calculating the costs or budgets allocated to the data management plan.

Repositories and platforms analysed

Global Health Data Exchange (GHDx)

Description

The Global Health Data Exchange (GHDx) is a data catalogue created and maintained by the Institute for Health Metrics and Evaluation (IHME). The GHDx directly supports IHME's mission to improve the health of the world's populations by providing the best information on population health. It was created as a dedicated place for anyone interested in global health and demographics to quickly find and share data information along with real data sets.

Main features

It brings together the world's most comprehensive catalogues of surveys, censuses, vital statistics and other health-related data. This database brings together health documents from more than 200 countries and can be searched by document type, country, organisation type, keyword, etc.

Disadvantage

It is created and funded by an Institute at the University of Washington.

OpenNeuro

Description

It is a free, specialised and open platform for the validation and exchange of BIDS-compatible MRI, PET, MEG, EEG and iEEG data with more than 29,000 participants and more than 700 public documents.

Main features

New material is added as researchers open their own data. Datasets are publicly available to promote research and better diagnosis in PET, MEG, EEG and iEEG data formats compatible with Brain Imaging Data Structure (BIDS).

Disadvantages

It is a neuroscience-specific repository.

GDC Data Portal GenomicData Commons

Description

The Genomic Data Commons (GDC) is a research programme of the National Cancer Institute (NCI). The mission of the GDC is to provide the cancer research community with a unified repository and cancer knowledge base to enable data sharing in cancer genomic studies in support of precision medicine.

The National Cancer Institute (NCI) GDC is a data-sharing platform that promotes precision medicine in oncology. It is not just a database or a tool; it is an extensible knowledge network that supports the import and standardisation of genomic and clinical data from cancer research programmes.

The GDC contains NCI-generated data from some of the largest and most comprehensive cancer genomic datasets, including The Cancer Genome Atlas (TCGA) and Therapeutically Applicable Research to Generate Effective Treatments (TARGET). For the first time, these datasets have been processed using a common set of bioinformatics pipelines so that the data can be directly compared as a growing system of cancer knowledge. The GDC also allows researchers to submit data. The GDC processes these data using bioinformatics pipelines to align the data to a common reference genome and to generate higher-level data such as variant calls and expression quantifications.

As more researchers add clinical and genomic data to the GDC, it will become an even more powerful tool for making discoveries about the molecular basis of cancer that can lead to better patient care.

Main features

It is the unified data repository of National Cancer Institute (NCI) genomic data. It enables data sharing among cancer genomics studies in support of precision medicine.

It supports multiple cancer genomics programmes at the NCI Center for Cancer Genomics (CCG), including:

- The Cancer Genome Atlas (TCGA),
- Therapeutically Applicable Research to Generate Effective Treatments (TARGET)
- The Cancer Genome Characterization Initiative (CGCI)

It provides a platform for querying and downloading high quality and comprehensive data. It provides a GDC data transfer tool and a GDC API for programmatic access.

REPISALUD

Description

REPISALUD is the HEALTH Institutional Repository of the Institute of Health Carlos III (ISCIII) and its foundations, the Spanish National Cardiovascular Research Centre (CNIC) and the Spanish National Cancer Research Centre (CNIO), which collects the scientific and academic production of these reference centres in their respective fields in a single digital archive with free access.

Main objective

- To increase the visibility, impact and transfer of the knowledge generated in these centres.
- To ensure the archiving and preservation of the deposited objects in full text, as well as their identification by means of a unique persistent identifier.
- To make it easier for the researchers in these centres to comply with the mandates of national and international funding bodies by allowing them to deposit all documents subject to this obligation in Open Access.

Main features

The content of REPISALUD is structured around five communities, which in turn are made up of sub-communities that group together the centres described and, where appropriate, their departments. These sub-communities are divided into the collections shown below, which contain the documents that can be included in the repository. These documents may be included in more than one collection to make it easier to find them using different search criteria.

RESEARCH: Articles, conference papers, research data, books and book chapters, patents, theses and research papers

INSTITUTIONAL: Reports and working papers, Dissemination material, Statements.

TEACHING Teaching material

SCIENTIFIC EVENTS: Meetings, Conferences and Congresses, Seminars,

EDITORIAL PROGRAMME Monographs and journals

RECOLECTA

Description

The Spanish Foundation for Science and Technology, F.S.P. (FECYT) and the Spanish University Libraries Network (REBIUN) of CRUE have developed a national platform (national aggregator of open access repositories) that brings together all the Spanish digital infrastructures in which research results are published and/or deposited in open access (RECOLECTA, or Open Science Collector).

The objectives of this platform include:

- To promote and coordinate the national infrastructure of open access digital scientific repositories and guarantee their interoperability according to the standards of the global community.
- To promote, support and facilitate the adoption of Open Access by all researchers in Spanish universities and R&D centres, the main producers of scientific knowledge in the country.
- To give greater national and international visibility to the results of research carried out in Spain.

In Spain there is an important infrastructure of resources for publishing and/or depositing research work in open access, consisting of institutional repositories, thematic repositories and open access journals.

RECOLECTA brings together all these resources in a single platform that guarantees their interoperability and allows access to the entire national scientific production in open access.

- Validator: It allows repositories to self-assess, as often as they wish, their level of compliance with international interoperability guidelines and to identify erroneous records.
- Collector: It aggregates metadata from repositories that are part of the RECOLECTA community on a weekly basis.
- Search Engine: It allows the search and free access to all openly accessible scientific production deposited in Spanish repositories through a single interface.
- The user support is through recolecta@fecyt.es

Main features

On this platform we find 169 repositories, of which 108 are institutional repositories, with more than 2.5 million open access documents and more than 28,000 research datasets.

ELIXIR

Description

ELIXIR is an intergovernmental organisation that brings together life sciences resources from across Europe. These resources include databases, software tools, training materials, cloud storage and supercomputers.

ELIXIR aims to coordinate these resources into a single infrastructure. This infrastructure makes it easier for scientists to find and share data, exchange knowledge and agree on best practices. Ultimately, it will help them gain new insights into how living organisms work.

TeSS is an example of an ELIXIR resource. TeSS is an online training portal that brings together life science training materials and courses from across Europe and allows them to be searched on one website. This makes it easier for scientists to find the training they need and gives training courses more visibility.

ELIXIR has 22 members and one observer, bringing together more than 220 research organisations. It was founded in December 2013 and started implementing its first scientific programme in 2014. It is currently implementing its second five-year scientific programme.

ELIXIR has compiled a list of resources it recommends for the storage of experimental data. The scientific community has a shared responsibility to ensure the long-term preservation and accessibility of data. The purpose of this list of repository databases is to provide guidance to policy and working practices makers on appropriate repositories for publishing open data in the life sciences.

Main features

This platform has an extensive list of biomedical databases as well as core data resources that can be used as a reference platform at European level for IIS.

In addition to these repositories, it may be interesting to collaborate with ZEONDO, a multidisciplinary repository.

ZENODO

Description

ZENODO has been designed and developed by researchers to ensure that everyone can participate in Open Science.

The OpenAIRE project, at the forefront of the Open Access and Open Data movements in Europe, was commissioned by the EC to support its emerging Open Data policy by providing a general repository for EC-funded research. CERN, an OpenAIRE partner and a pioneer in open source, open access and open data, provided this capability and ZENODO was launched in May 2013.

In support of its research programme, CERN has developed tools for Big Data management and extended the capabilities of the Digital Library for Open Data. Through ZENODO, these Big Science tools have been effectively shared with the long tail of research.

Main features

- It was promoted by the European Commission through the OpenAire project and hosted at CERN (which provides security for the future of the hosted data).
- It complies with FAIR criteria.
- It is free.
- It allows DOI reservation.
- It is integrated with ORCID, allowing integration with the ARGOS platform (a DMP management tool).
- It allows 50GB of information to be uploaded per publication.
- It assigns Creative Commons licences, links data to a call for papers, etc.
- By publishing in ZENODO, the requirements of national and international calls (Horizon Europe, etc.) would be met.

With regard to the professional profiles that can develop this type of functions at present (data managers), figures have been identified, as well as specific courses to develop specific skills in this field.

Among the professional profiles that can act as data managers, we find:

- Librarian/documentalist specialised in health sciences.
- Degree in Information and Documentation
- Degree in Data Science
- Master's degree in Big Data

Interdisciplinary working groups could also be set up, including computer scientists, mathematicians, biologists, etc.

What we consider important is not so much the profile, but the training of the people who will be in charge of this subject in each IIS; these training actions should be centralised by the ISCIII.

On the other hand, as there are also calls for the recruitment of technical staff in bioinformatics with research management contracts, calls for the recruitment of data managers should be launched.

Conclusions and Suggestions

Objective 1

All the tools are based on free software for individual use, with the exception of DSW, which is not free for institutions. The use of a free software tool allows the tool to be adapted and customised to the needs of the institutions: development of new functionalities, new templates, new languages, etc.

None of the tools includes specific sections for health science projects, although some (Argos) have included specific sections in their templates, particularly in relation to the management of personal data in accordance with current legislation. It would be advisable to develop templates that include texts to support compliance, exploring the possibility of this activity being managed centrally by the ISCIII.

Only one tool takes into account the economic management involved in the development of a data management plan: EINA.CORA

Most of the tools support the generation of a first version of the DMP, although some also include the functionality to deposit the generated data in public repositories: EINA.CORA and ARGOS.

Objective 2

We recommend that efforts to create new repositories should not be duplicated, as there are many national and international repositories grouped by type of data, and that efforts should be focused where repositories for specific data or disciplines do not yet exist.

We also recommend to researchers the need to use existing repositories, rather than trying to create a new repository with specific characteristics, as repositories should bring together the data of each scientific field, depending on the field of research. It could be useful for researchers to have a list of repositories according to the type of data they hold, as has been done by other initiatives such as ELIXIR.

If it is strategically appropriate to develop a new repository, because a specific need is identified that is not covered by the current repositories, this working group proposes that it should be part of the REPISALUD data platform. It could be developed in a national or international context, depending on the nature and complexity of this new repository. This platform can be integrated with the Recoleta platform so that the data collected are interoperable according to global community standards.

Regarding the professional profiles of the data managers, they should be professionals with the following profiles

- Librarian/documentalist specialised in health sciences.
- Degree in Information and Documentation
- Degree in Data Science
- Master's degree in Big Data

It is important to carry out training activities, centralised by the ISCIII, aimed essentially at profiles related to data management, with the aim of ensuring that the staff in charge of data management in the IIS acquire the necessary skills according to the repository or platform selected and/or developed by the ISCII for the data management of the IIS. Similarly, as a complement to strengthening the inclusion of specialised profiles, the publication of specific calls for grants aimed at recruiting data managers in the IIS is considered positive.

Objective 3

Almost 50% of the institutions do not have a data manager. It is considered a priority to promote this figure within the IIS and to offer training to enable them to carry out their work adequately, both as data managers and as promoters within the institution.

Most institutions do not offer training in data management, and if they do, it is generic and aimed at all staff. The training priorities requested by the institutions include generic training, but also more practical and specific training, with workshops or short courses to enable the effective implementation of data management plans.

Most of the training received was provided by the ISCIII. It would be advisable for the ISCIII to continue developing such training, both generic and more practical, regardless of whether the institutions include it in their training plans. In order to promote and harmonise training in the centres, both basic and specialised, it would be advisable for the ISCIII to carry out "training of trainers" activities with the aim of making the institutes autonomous.

In addition, training could be promoted for other profiles responsible for the extraction, anonymisation and preparation of data for inclusion in the repositories, as well as on aspects related to the protection of personal data, given their particular relevance in the field.

Participation of Non-Scientific Actors in IIS Activities

GT3. *Institute Partnership*. 2022.

Coordination: ibs. GRANADA

Manager: Dr. María José Sánchez. Scientific Director: ibs.GRANADA

Executive Summary

This document presents a proposal/guideline for the participation of non-scientific actors in the research process within the IIS.

The objective was to propose a strategy for the participation of non-scientific key actors in the activities of the IIS by identifying and defining the different levels of involvement of non-scientific key actors in the IIS and proposing strategic objectives, recommended actions, indicators for monitoring and follow-up and a timetable for each level of involvement.

The document was prepared with the support of the scientific and technical staff of 11 accredited IIS.

The situation of the admission of key non-scientific actors in the IIS was analysed by studying the visibility of Responsible Research and Innovation (RRI) in the IIS and by collecting information through a survey in order to identify good practices carried out by the IIS in relation to the admission of key non-scientific actors.

As a main result, a strategic plan based on a balanced monitoring system for the participation of non-scientific actors in IIS will be proposed, defining (according to the different levels of involvement of non-scientific actors in IIS):

1. Strategic objectives.
2. Recommended actions.
3. Monitoring indicators.
4. Timeline.

Finally, a series of general recommendations are proposed for the ISCIII, with the aim of promoting the active participation of the private sector and civil society in research, development and innovation, as well as the social recognition of science through the scientific education of society, the dissemination of science and technology and the participation of citizens in scientific decision-making.

Introduction

The need to involve key non-scientific actors in the research process is an aspect that is becoming increasingly important in the research agenda, in what is known as RRI. However, their systematic and structured involvement in research processes and/or their visibility as key elements in research still leaves much room for improvement.

If we had to highlight the main reasons for including key non-scientific actors in the IIS and justifying their integration in the research process, we could highlight the following:

- The strategic plans of the main public research organisations include among their strategic objectives the promotion of the participation of patients and citizens in research policies, as recipients of the scientific process.

- Existing funding programmes of the European Union and other international organisations increasingly take into account the participation of society in research policies. Indeed, the conference on the Future of Europe, which will define the strategic guidelines of the European Union for the coming years, was based on a participatory process involving European citizens. Its final report, based on the work of various citizens' panels, was presented on 22 May 2022 and contains proposals directly related to health research (<https://futureu.europa.eu/es/>).
- The involvement of citizens in research, beyond the researchers themselves, increases the non-academic impact of research results. The greater the involvement of key non-scientific actors, the greater the impact.
- The involvement of non-scientific actors in research processes can serve as a bridge between science and society, moving from 'science and society' to "science IN society" and then to "science WITH and FOR society".

Key actors in the research system and participation in research

As **ACTORS OF THE SYSTEM**, we include those people or organisations who are not researchers, but who can contribute to or receive value from the research carried out, whether as beneficiaries, health professionals, policy makers, managers, industry, civil society organisations, NGOs, patients or citizens. The latter are undoubtedly its end users.

The "MONITORING SYSTEM OF ACCREDITED IIS: INSTRUCTIONS" document for the year 2022 defines what is meant by **NON-SCIENTIFIC KEY ACTORS**:

"People who do not carry out research or R&D&I management and who can add value to scientific activity by playing a role both in the scientific process and in the 'destination', 'benefit' or use of the results of it.

This is understood independently of the mechanism of inclusion as a non-scientific actor, whether at the suggestion of organisations (scientific societies, NGOs, patients' associations, etc.) or by personal invitation".

With regard to the way in which the non-scientific key actors in the system participate in research, we can distinguish four levels, depending on the degree of their interaction:

1. **INFORMING**: Unidirectional interaction in which the research activity is communicated to the different actors of the system with balanced and objective information.
2. **CONSULTING**: Researchers obtain the point of view of system actors on key aspects of the research.
3. **INVOLVING**: Work is carried out in a bidirectional (dialogue) and direct manner with actors, so that aspirations and concerns are jointly understood and taken into account before decisions are made.
4. **CO-CREATING**: Work is carried out collaboratively and multidirectionally, collaborating with different actors in the system on each aspect of the decision.

Theoretical Framework

The incorporation of non-scientific key actors in the research process has emerged as an innovative practice to address complex problems that require the participation of multiple perspectives. These actors include patients, communities, politicians, non-academic professionals, non-governmental organisations (NGOs) and others, who bring knowledge and practical experience that can complement the vision of traditional scientists. This approach aims to enrich the research process, improve the relevance of results and facilitate the transfer of knowledge for more effective action.

Collaboration with non-scientific actors is also linked to the growing demand for more interdisciplinary, transdisciplinary and participatory research, which promotes the inclusion of broader perspectives in identifying problems and formulating solutions. Such approaches are crucial in areas such as public health, climate change, education and sustainable development, where social, economic and political challenges are inextricably linked to scientific issues.

Definition and key concepts

The incorporation of non-scientific actors into the research process refers to the active participation of individuals or groups who do not have formal academic or scientific training, but whose experience and knowledge are relevant to the problem. These actors include:

- Patients and carers in health research.
- Local communities in sustainable development or environmental studies.
- Private sector professionals, such as industrialists, businessmen or opinion leaders.
- Government officials and decision-makers in areas such as public policy and economics.

The key term here is co-production of knowledge, which according to Jasanoff (2004) refers to the collaborative process by which scientists and non-scientific actors jointly contribute to the creation of new knowledge. Co-production recognises that scientific knowledge is not the only valid form of knowledge and that the interaction of different forms of knowledge, such as local and traditional knowledge, can lead to more comprehensive and applicable solutions.

Related theories

The participatory action research (PAR) approach is one of the key theories emphasizing the involvement of non-scientific actors in research. According to this approach, developed by Lewin (1946), research seeks not only to generate knowledge but also to bring about social change. In this context, non-scientific actors are not only objects of study, but active co-researchers who help formulate research questions, collect data and reflect on the results. PAR promotes a cyclical process of reflection and action in which collaboration and participation are fundamental.

Transdisciplinarity, on the other hand, is a theoretical approach that promotes the integration of multiple disciplines and the participation of actors outside the academy in research. According to Max-Neef (2005), this approach seeks not only to combine different fields of knowledge, but also to go beyond the boundaries of science to include knowledge from everyday life, local experiences and practical concerns. In the framework of transdisciplinarity, the inclusion of non-scientific actors is justified as a means to solve complex problems that cannot be addressed from a single disciplinary perspective.

Benefits of involving non-scientific actors

Numerous studies have shown that involving non-scientific key actors in the research process can improve both the quality and relevance of the results. In health research, for example, patient involvement has been shown to have a positive impact on the design of studies that are more responsive to the needs of end users. Shippee et al. (2015) highlight that patients can identify research priorities that may be overlooked by scientific researchers, making studies more meaningful and applicable.

Challenges of involving non-scientific actors

Despite the potential benefits, the inclusion of non-scientific actors also presents significant challenges. One of the most common issues is the power asymmetry between scientists and non-scientific actors. Scientists tend to have greater control over study design and interpretation of results, which can lead to superficial involvement of non-scientific actors. According to Cornwall (2008), it is essential that mechanisms are developed to ensure more equitable and meaningful participation, where the knowledge and perspectives of all actors are fairly valued.

Another challenge is the lack of familiarity of non-scientific actors with scientific methods. This can limit their ability to contribute fully to the research process. However, providing appropriate training and building trust between scientific and non-scientific actors can help to overcome this barrier.

Impact of incorporating non-scientific actors

The involvement of non-scientific actors has the potential to transform the research process and produce more inclusive and actionable results. In health care, the active involvement of patients and carers has been shown to improve the implementation of treatments and policies that better meet the real needs of users.

Conclusions

The involvement of non-scientific actors in the research process offers many benefits, but also poses significant challenges. While the involvement of these actors can enrich the research process, it is critical to ensure that collaboration is equitable and that power differences are appropriately managed. With an inclusive and participatory approach, the co-production of knowledge can significantly improve the relevance and applicability of research results and contribute to the creation of more effective solutions to complex problems.

Methodology

1. SOURCES OF INFORMATION

Following a literature review to develop the strategy and propose indicators, the following documents were used as a starting point:

- The criteria of the Technical Guide for the Evaluation and Accreditation of the IIS related to a dimension of RRI, and in particular those directly related to the dimension of citizen participation and key actors.
- A list of 47 indicators derived from the monograph SARIS No. 1 (Responsible Research Series) (Arrizabalaga et al., 2018), which reports the results of a literature search in scientific journals and grey literature for indicators of non-scientific actors involvement in health research at the international level. Indicators were collected to analyse the involvement of non-scientific actors in research at the level of the research institution (e.g. university, research centre, health research institute). The indicators were grouped according to the dimension of non-scientific key actors involvement (governance, capacity building, resources, activities, dissemination and primary outcomes) and the characteristics of each indicator. These characteristics included the dimensions of relevance, or the proximity of the indicator to the core content of the concept of actor involvement, i.e. the extent to which the involvement measured by the indicator is real, and feasibility, or the extent to which the data to construct the indicator are available and affordable.

- A list of 7 RRI indicators adapted to the Spanish science system (Garcia-Melón et al., 2022). Using a participatory and deliberative methodology, based on the participation of a group of experts composed of different actors of the system, Garcia-Melón et al. adapted it to the Spanish context and selected 7 indicators related to the participation of non-scientific key actors as the most important ones: 1) Existence of specific calls for the development of projects by citizens or non-academic organisations. 2) Satisfaction of citizens' expectations following their participation as non-scientific key actors in public participation processes. 3) Percentage of people having participated in projects/initiatives involving non-scientific key actors. 4) Existence of incentives for researchers or mechanisms for official recognition of participation in public participation processes. 5) Participation of non-scientific key actors in public consultations on science, development and innovation policies. 6) Participation of non-scientific key actors in councils and committees. 7) Total resources devoted to public participation (at national level).
- The Strategic Plan for the Involvement of Non-Scientific Key Actors of the NIHR School for Public Health in the United Kingdom. This document, in its 2019 update, contains the strategy for the incorporation of non-scientific key actors in the activities of this UK institution. As an institution, the NIHR School for Public Health shares many characteristics with the Institute of Health Carlos III and therefore offers a developed strategy that could serve as an example. The objectives of the strategy are linked to specific recommended actions, expected outcomes and timelines for progress.
- The analysis of good practices and the results of the survey on the involvement of non-scientific key actors sent to the IIS (see part 1 of this report, 6.2.2. Analysis of the involvement of non-scientific key actors in the IIS).

2. DEVELOPMENT PROCESS

For the development of the proposed Strategic Objectives, a sub-working group was created within ibs. GRANADA. The sub-working group produced a first draft which was sent to all GT3 representatives and the GT6 coordinator, and subsequently to all ISCIII accredited IIS, for review and suggestions.

This group worked in coordination with the IIS Partnership Working Group 6 on Support plans for the dissemination of science in non-scientific areas: role of researchers, led by the Health Research Institute Gregorio Marañón (IiSGM).

Development and Results

1 REVIEW OF THE TECHNICAL GUIDE FOR THE EVALUATION AND ACCREDITATION OF THE IIS

A review was carried out of the criteria of the Technical Guide for the Evaluation and Accreditation of the IIS, which in one way or another relate to some of the dimensions of Responsible Research and Innovation, RRI (ethics, gender, governance, open access and science education), according to the dimension of RRI to which they refer or are related.

An analysis of these criteria (see analysis in Appendix V) shows that the involvement of non-scientific key actors has a particular impact on the dimensions of public participation, science education and, to a lesser extent, governance.

RRI Area	Number of associated criteria	% of associated criteria
Ethics	11	22%
Gender equality	6	12%
Governance	30	61%
Open Access	10	20%
Citizen participation	11	22%
Science education	12	24%
Total RRI criteria	49	

2. STATE OF THE PARTICIPATION OF NON-SCIENTIFIC KEY ACTORS IN THE IIS

2.1. Analysis of the visibility of RRI in the IIS

Of the 34 accredited IIS, it was verified which ones have public information about non-scientific key actors on their website. Only 7 IIS include some kind of information on non-scientific key actors, mainly in the dimension of citizen participation and governance.

The positioning and visibility of public information on the website and its positioning in relation to the other RRI principles was also analysed. Only 10 include a section with information on the different dimensions of RRI in their institute, with very heterogeneous content.

2.2. Analysis of the participation of non-scientific key actors in IIS

In order to analyse the situation and identify good practices, the working group developed and sent out an online questionnaire via Limesurvey (see Appendix II), which complements the quantitative information available on the IIS website analysed in point 2.1. The results are shown below.

Block 1: IDENTIFICATION OF NON-SCIENTIFIC KEY ACTORS

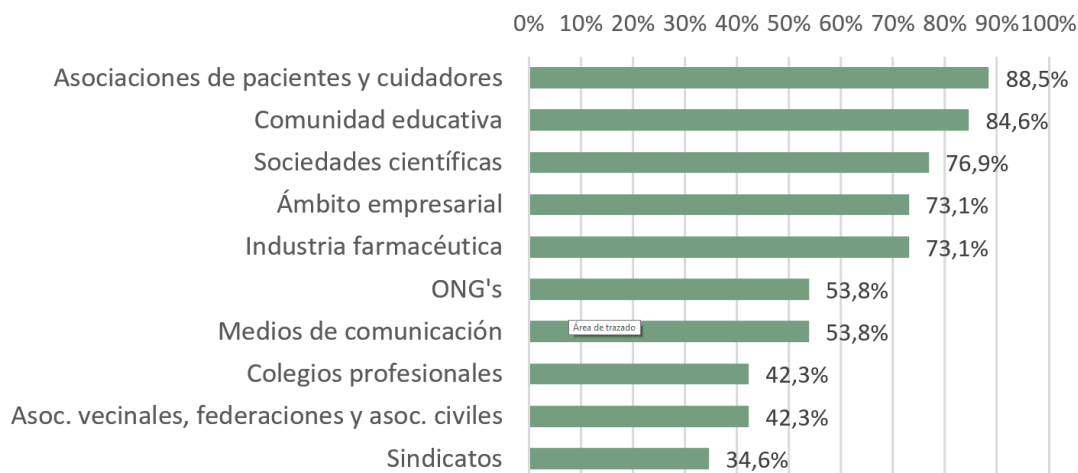
The first block of questions aims to identify the non-scientific key actors currently or potentially involved in the activities of the IIS.

The response rate was 76.5%, with 26 of the 34 IIS to which the survey was sent responding.

Just over half of the research institutes (54.2%) indicate that they provide information on their website about mechanisms for public participation.

The majority of institutes agree that patient and carer associations could be involved as important non-scientific key actors in their research institutes (88.5%) (Graphic 1). The educational community (identified by 84.6% of institutes), scientific societies (76.9%) and the pharmaceutical industry or business community (both 73.1%) were also identified by a majority of institutes.

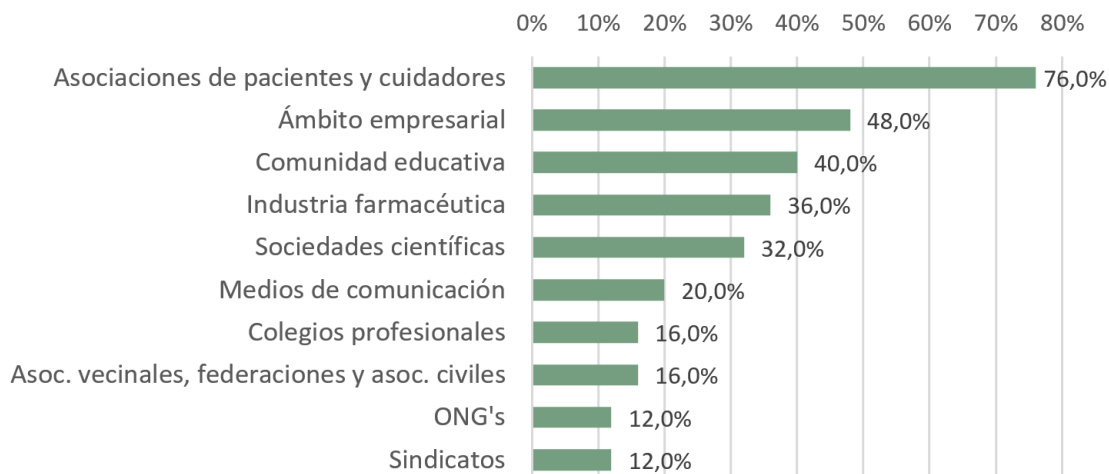
Gráfico 1. Institutions or entities that could be involved as non-scientific key actors.



In addition, the general public -not necessarily patients or associations-, professionals from other sectors, local councils or banks were mentioned by several institutes as other possible non-scientific key actors.

Patients' and carers' associations are the only key actors currently involved in the activities of most institutes (76.0%). The other potential key actors have a much lower presence, less than 50% of the total of institutes, with business environment (48.0%), educational community (40.0%), pharmaceutical industry (36.0%) or scientific societies (32.0%) (Graphic 2) standing out.

Gráfico 2. Current participation of non-scientific key actors.



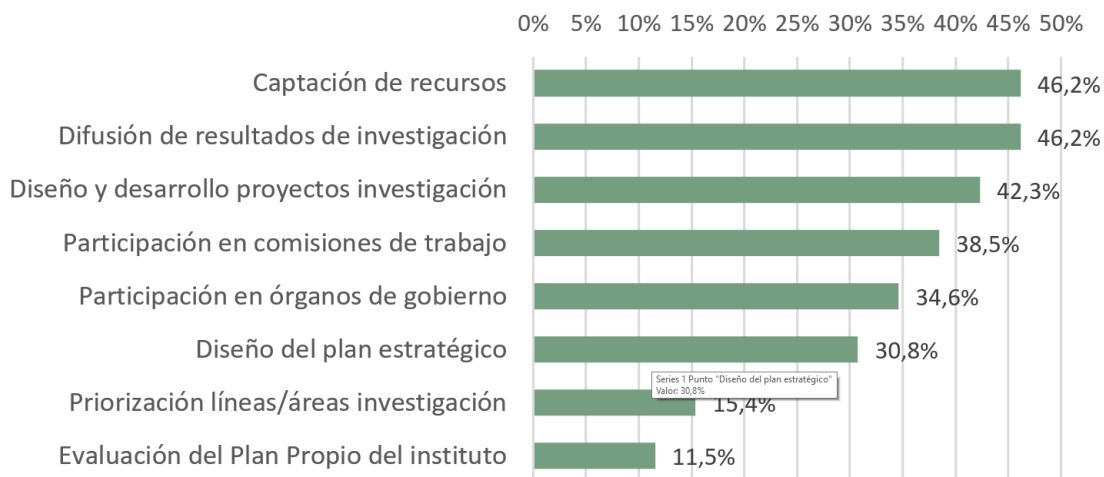
Some institutes also have representatives of European organisations in their governing bodies -e.g. the European Patients' Forum-, lawyers and economists in the Research Ethics Committee (REC), a lay member also in the REC, or local councils.

In addition, one institute reports that there is currently no involvement of non-scientific key actors in its activity.

In 61.5% of cases, non-scientific key actors were involved in the activities of the institutes at the personal invitation of the governing bodies, and in 50.0% of cases at the proposal of the research groups. In 30.8% of cases, the working committees proposed the inclusion of these key actors, and in 15.4% of cases it was the actors themselves who requested their inclusion.

The majority of non-scientific key actors were involved in fundraising (46.2%), either -by organising fundraising campaigns and donations, channelling the use of funds raised by associations or providing resources and direct aid, participating in the design, development and dissemination of research projects (42.3% and 46.2% respectively), being part of working committees (38.5%) or being part of governing bodies (34.6%) – governing councils, boards of trustees, internal scientific committee (ISC), scientific advisory board, business council, external advisory bodies, etc. (Graphic 3).

Gráfico 3. Level of involvement of non-scientific key actors.



When analysing the comments on the participation of non-scientific key actors in the design and development of research projects, it is noted that this contribution has focused on expressing needs, shortcomings and opinions that can guide the lines of research, and also on building bridges for the participation of other actors in the projects, such as patients.

In the case of the dissemination of these projects, non-scientific key actors have contributed by organising conferences, lectures and dissemination sessions or by using their own social networks.

Comments on working committees involving non-scientific key actors include regular meetings to discuss priorities, internal scientific committees, research committees, ethics committees, innovation committees, working groups on gender equality, clinical research and training, etc.

In addition, other activities such as training sessions, activities in local schools and open days have been organised in collaboration with non-scientific key actors.

The questionnaire also asked about how they have been involved in the design and development of research projects. The majority of institutes reported that they involved non-scientific key actors (72.7%):

“There was collaboration with them to apply for competitive funding”.

“They have been consulted, they have been involved, and when results have been obtained, a special day has been organised for the participants”.

“In the assessment of calls for intramural grants, in the mentoring of innovation projects and in the evaluation of groups’.

“Through dissemination and the request for communication of needs, quality of life surveys and plans to develop strategies for improvement in the social health field”.

In addition, co-creation activities or actor consultation took place in 54.5% of cases and information was provided in 36.4% of cases (e.g. prior information sessions or presentations at specific congresses).

“Projects have been developed with patient associations, taking their views into account”.

“They were consulted in the development of the project”.

“Through surveys”

“They are consulted on calls for proposals and strategic projects”.

“Workshop with participants to analyse surveys”.

“Co-creation projects have been developed with patients to improve healthcare activity”.

“IRYCIS Mission Programme in co-development with members of the Innovation Committee”.

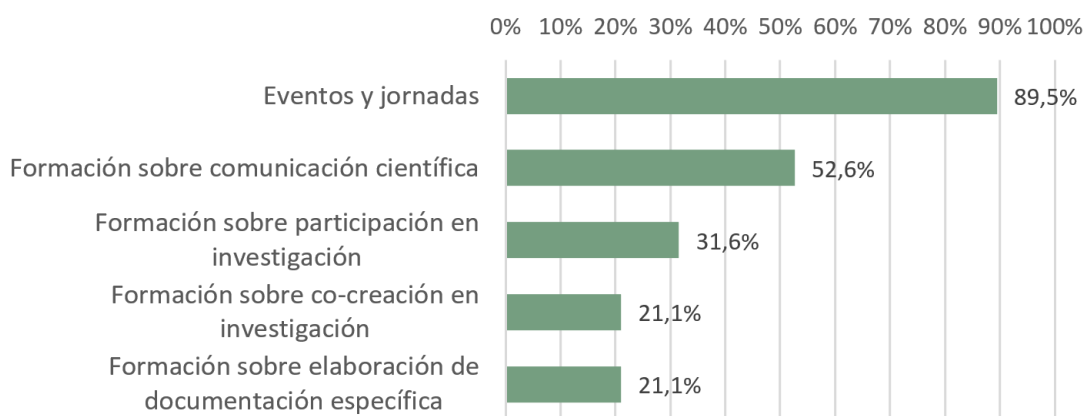
“Communication meetings on advances in knowledge and innovative actions”.

Block 2: GOOD PRACTICES IN PROGRESS

21.7% of the institutes that responded to the questionnaire have a plan for the translation of scientific results into the clinical practice and the productive sector that includes actions to involve non-scientific key actors.

A large majority of institutes have organised events and conferences aimed at non-scientific key actors (89.5%). The percentages are lower for training activities on scientific communication (52.6%) or participation in research (31.6%) (Graphic 4).

Gráfico 4. Training activities for non-scientific key actors



Among the events and conferences organised, the following were mentioned: Science Week, European Researchers' Night, visits for patients and patients' associations, talks at the Casa Golferichs (civic centre), Generació Ciència programme for schools, Beer for Science, Pint of Science and open days, Science Day, Biojunior Day, dissemination exhibition "Another look at research", Innovation Week, Mural of Women Scientists, Participation of researchers in city events, participation in business forums and fairs, presence in non-scientific media, hands-on visits to the centre for secondary and primary school students, Women and Girls in Science, drawing competitions for primary school students, etc.

Training activities included: training on dissemination to non-scientific audiences, specific training for researchers on science communication, a 12-hour course on 'Disseminating science, disseminating evidence' and a course on social communication of science.

More than half of the Health Research Institutes organise these training activities and conferences annually (56.5%), occasionally (21.7%), twice a year (13.0%) and every two years (4.3%).

When analysing the channels of public participation used to involve non-scientific key actors, 73.9% of institutes organise open days, 69.6% use social networks, 47.8% use specific forums and 30.4% use contact forms.

In addition, the Social and Business Council, direct contacts, working groups, websites, drawing competitions, etc. are used for public participation.

When asked about the specific forums in which the Institute participates, the following were mentioned: Researchers' Night, Science Week, working sessions and dialogues between doctors and patient associations, open research seminar, patient days, student congresses, forums for discussion and dissemination of research in the region, conferences for the general public, international days of different diseases, patient association conferences, community meetings, forums organised or attended by the RRI Commission, CIBERSAM meeting between mental health researchers, patients and families, 'We are patients' day, annual 'Multiple Sclerosis and Society' day, Health between Cultures project (to contribute to the integration of the immigrant population), Lung Cancer Patient Days, RenalTú project, Forum for Patients with Primary Tubulopathies, etc.

Finally, 21.7% of the institutes have tools to assess the satisfaction of the non-scientific key actors involved in the different phases of the research activity. Questionnaires are used, as well as a suggestion box and specific working groups, which make it possible to carry out assessments with a very heterogeneous periodicity: after each event, every six months, annually, bi-annually or on an ad hoc basis.

Block 3: DESIRABLE GOOD PRACTICES

Other good practices promoted by the different IIS in relation to the involvement of non-scientific key actors are listed below:

- Science education: dissemination activities, participation in the Masters in Health Management, science and research training programmes, open days, guided tours of facilities, participation in the Researchers' Night, specific training in RRI, participation in the Microworld programme, science workshops with students, etc.
- Citizen participation: fusion programme for intra-entrepreneurship in health, information for patients on trials in which they can participate, participation through micro-patronage: Colabora campaign,

Evaltec programme based on human factor science to evaluate health technologies, Tichron project based on the use of new technologies in children with chronic diseases, etc.

- The inclusion of specific objectives related to RRI actions (including citizen participation) in the specific plans of the Joint Science project, so that the researchers themselves are able to find the most appropriate type of actor with whom to collaborate, and so that it is not just a decision or strategy on the part of the management.
- Weekly scientific seminars and forums open to society in order to seek possible synergies and collaborations with other groups of actors.
- Platform presentation days open to all types of audiences. The updates of the Guide to Good Practices in Research are presented publicly. Intramural call assessment panels include non-scientific key actors. The review of the Joint Scientific Plan in October included contributions from scientific societies, professional associations, patient and family associations and related companies.
- Prevention campaigns, existence of an Advisory Committee of Social Actors (CAAS).
- The Manual of Good Practice includes guidance on research involving human samples and the protection of personal data: “All research involving the participation of individuals, the use of human biological samples or personal data will never be initiated without prior review by a Research Ethics Committee (REC), as set out in the Law on Biomedical Research (LIB). “Personal data will only be used for the purposes for which they were collected. Therefore, the transfer of personal data will be carried out in the manner and with the limitations and rights established in the Organic Law on the Protection of Personal Data (LOPD)”.
- Participation in national and international forums to involve non-scientific key actors. Promotion of European projects such as EUPATI and EATRIS.
- Development of the e-DUCASS project on food education in the most deprived areas.
- CORDIOPREV project, on the benefits of EVOO in improving cardiovascular diseases.
- Collaboration in the FIDICIENCIA project, based on immersing students in scientific competence.
- Organisation of school visits to IMIBIC for high school students and students in scientific professional training.
- Workshops for innovation teams.
- Participation of non-scientific actors the Ethics Committee.

Actions aimed at explaining the projects funded by La Marató of TV3 to the public. Lecture modules in the city's civic centres.

Scientific workshops for the public on open days.

- A programme, “12 months looking after you”, is being developed for the general public, with monthly conferences to which patient groups are invited. In addition, dissemination activities are carried out in schools.

- In addition to the above-mentioned participation of a lay member in the research ethics committee, the Institute has organised two important activities this year within the framework of the European project “MEDNIGHT SCI-DATES”.

On the one hand, visits to the Centre were organised for primary and secondary school students to experience first-hand scientific discovery and the work of a health professional. In addition, a two-day event was organised to bring us closer to Alicante society and to promote the approach and participation of non-scientific key actors in the life of the Institute (<https://isabial.es/evento/cita-con-los-investigadores-sci-dates/>).

Meetings with researchers repeats the offer of workshops for the school public in the morning, two days, opening the offer to the general public in the afternoon of the first day. In addition, there is always an exhibition with information on the 43 research groups, which also meet the general public on the afternoon of the second day, so that they can have a direct encounter with scientists through round tables, workshops, video presentations and simulators, among other activities.

- Activities aimed at establishing meetings with non-scientific key actors.
- The Institute's Board of Trustees has a strong representation from Valencian society, including patient associations such as FEDER (Federation of Rare Disease Patients) and the FEDER Foundation.
- Training in scientific communication for researchers.
- Visits for patients and patient associations. Workshops for schools.
- Planning of co-creation training actions with non-scientific key actors. Dissemination of RRI principles. Definition of an Open Science policy.
- Non-scientific key actors will be invited to participate in the governing bodies or advisory committees.
- The external innovation advisory board includes non-scientific actors. We also have non-scientific actors on our Board of Trustees.

On some occasions, we have collaborated with various patient associations to design studies, informational events or to better disseminate their work.

- Open days organised by the ISCIII, the Ministry of Science or the Autonomous Communities, in which researchers from the different IIS can participate to disseminate science, taking advantage of their greater convening power.

Support from the ISCIII and/or the Ministry of Science for the dissemination of scientific and innovative advances of the IIS.

Finally, among the suggestions regarding the involvement of non-scientific key actors in the IIS, participants commented that:

“The IIS could be grouped together to try to facilitate the accompaniment of those of us who are in a more incipient situation in this field”.

“We are working on a new website for ISPA, which will include content and spaces aimed at citizens, as well as tools for communication and participation of non-scientific key actors in the development of our Institute's research and innovation activities”.

Proposal for the Involvement of Non-Scientific Key Actors in the IIS: Strategic Objectives, Actions and Monitoring Indicators

1. OBJECTIVE

The objective was to propose a strategy for the participation of non-scientific key actors in the activities of the IIS by identifying and defining the different levels of involvement of non-scientific key actors in the IIS and proposing strategic objectives, recommended actions, indicators for monitoring and follow-up and a timetable for each level of involvement.

2. DEFINITIONS AND SELECTION CRITERIA

Non-scientific key actors were considered as "people who do not carry out research or R&D&I management and who can add value to scientific activity by playing a role both in the scientific process and in the 'destination', 'benefit' or use of the results of it. This is understood independently of the mechanism of inclusion as a non-scientific actor, whether at the suggestion of organisations (scientific societies, NGOs, patients' associations, etc.) or by personal invitation".

The following levels of involvement of non-scientific key actors in the IIS have been identified and defined:

- **GOVERNANCE:** Participation in the process of planning and defining strategies, organisation and management.
- **RESOURCES AND PROJECTS:** Resources, financial or human, dedicated to the involvement activities of actors or resources obtained from the actors. Interaction of research activities with non-scientific key actors such as funders and/or collaborators in projects.
- **TRAINING:** Training and upgrading of skills for both non-scientific key actors and research staff to carry out research participation activities. Training activities for research staff will be addressed by GT6.
 - **DISSEMINATION:** Translation of research taking into account non-scientific key actors and their interaction.
- **PRIMARY OUTCOMES:** Products and services realised in a participatory manner with non-scientific key actors on the basis of research results.

Recommended actions refer to the establishment, improvement and/or maintenance of specific practices, activities and/or resources that can contribute to the achievement of the proposed strategic objectives.

By indicators we mean variables that measure, quantitatively or qualitatively, the main aspects reflecting the degree and quality of involvement of non-scientific key actors in the IIS.

In the indicator selection process, indicators were prioritised and adapted to be:

- (1) relevant, realistic and feasible, based on the current situation of the IIS, according to the analysis of good practices, and
- (2) measurable in the current context of the IIS to allow for effective follow-up and monitoring.

An order of priority has been established for the indicators included in each dimension, starting from those considered most important and/or general to those considered less important and/or more specific.

3. LEVELS OF PARTICIPATION AND PROPOSED STRATEGY

3.1. Governance

3.1.1. Strategic objective

To involve non-scientific key actors in the mission, the planning and the definition of the strategy, and the organisation and management of the IIS.

3.1.2. Recommended actions

- To include the participation of non-scientific key actors in the mission of the Institute.
- To involve non-scientific key actors in the planning, development and/or review of the Institute's strategies, policies and/or action plans.
- To include representatives (associations, patients, carers, community, etc.) of non-scientific key actors in the Institute's governing bodies, commissions, working groups and/or evaluation committees.
- To encourage and support the establishment and maintenance of institutional and cooperation agreements with external organisations led by or involving non-scientific key actors (e.g. associations, NGOs, companies...).
- To encourage the diversity of non-scientific key actors involved in the IIS.

3.1.3. Indicators

Order of priority	Indicator
1	Participation of non-scientific key actors is included in the mission of the Institute.
2	Number of strategies, policies and/or action plans in which non-scientific key actors have been involved. (Participation in prioritisation of research lines, joint science project, strategic plan, dissemination plan, training plan or resource raising).
3	Number of representatives of non-scientific key actors (associations, patients, carers, community, etc.) included in the institute's governance bodies.
4	Number of representatives of non-scientific key actors (associations, patients, carers, community, etc.) on the institute's commissions, working groups or committees.
5	Number of internal calls for proposals (e.g. intramural projects, awards, etc.) involving non-scientific key actors in the evaluation committee.
6	Number of institutional cooperation agreements of the IIS with associations, communities, etc.
7	Number of IIS agreements with companies facilitating the involvement of non-scientific key actors in the different IIS.

3.1.4. Timeline

(See Appendix IV)

3.2 .Resources and Projects

3.2.1. Strategic objectives.

- To obtain and/or maintain financial or human resources dedicated to the engagement activities of non-scientific key actors or resources obtained from the actors for research purposes.
- To involve non-scientific key actors in the research process.

3.2.2. Recommended actions

- To establish and/or maintain a budget (€€€) and appoint qualified staff dedicated to non-scientific key actors involvement in the activities of the institute.
- To facilitate and encourage applications for funding in calls for proposals initiated by non-scientific key actors organisations or associations (NGOs, patient associations...) by disseminating information on relevant calls for proposals and/or by providing effective support in the application process.
- To include elements of non-scientific key actors participation as an evaluation criterion in the Institute's internal calls for proposals (intramural projects, awards, recognition, etc.).
- To coordinate with hospitals, universities and other related institutions to share actions for the participation of non-scientific key actors.
- To encourage the participation of non-scientific key actors in the design, development and execution of research projects.

3.2.3. Indicators

Order of priority	Indicator
1	Institute's budget dedicated to the participation of non-scientific key actors.
2	Number of staff dedicated to managing non-scientific key actors involvement as a specific part of their work.
3	Funding obtained from calls for proposals launched by non-scientific key actors associations or bodies (NGOs, patients' associations, etc.).
4	Funding requested from calls for proposals launched by non-scientific key actors associations or bodies (NGOs, patients' associations, etc.).
5	Number/percentage of projects in which an association, NGO, etc. was involved in the planning phase of the research.
6	Number/percentage of projects in which an association, NGO, etc. was involved in the development and implementation phases of the research.
7	Number of internal calls for proposals (e.g. intramural projects, awards, mobility, etc.) which include elements of non-scientific key actors involvement as an evaluation criterion.

* Implementation phase refers to any of the many possible tasks in the research process, from recruitment of participants to dissemination of results.

3.2.4. Timeline

(See Appendix IV)

3.3. Training:

3.3.1. Strategic objective

To carry out activities aimed at facilitating the training and upgrading of skills for both non-scientific key actors and research staff to carry out research participation activities.

3.3.2. Recommended actions

- To organise training activities for different non-scientific key actors (patients, decision-makers, etc.).
- To organise training activities for researchers and/or managers on the involvement of non-scientific key actors in the different phases of research.
- To disseminate information on external activities aimed at researchers on the involvement of non-scientific key actors in the different phases of research.
- To promote and encourage the training and participation of researchers in external organisations led by or involving non-scientific key actors, such as associations, NGOs and companies.

3.3.3. Indicators

Order of priority	Indicator
1	Number of training activities targeted at different non-scientific actors in the system
2	Number of training activities on science communication aimed at researchers*.
3	Number of training activities aimed at participation and/or co-design activities of non-scientific key actors in the research planning phase (research design and/or implementation).
4	Number/percentage of staff working temporarily in external organisations (associations, NGOs, companies, etc.).
5	Number of doctoral theses and masters carried out in collaboration with external organisations (associations, NGOs, companies, etc.).

*These could be activities organised by the institute itself or external activities involving researchers from the institute.

3.3.4. Timeline

(See Appendix IV)

3.4. Dissemination:

3.4.1. Strategic objective

To consider and involve non-scientific key actors in the dissemination of research.

3.4.2. Recommended actions

- To participate in and/or regularly organise dissemination activities that allow interaction and/or participation of non-scientific key actors (e.g. science cafés, science festivals, researchers' nights, open days, public lectures, press releases, radio or TV interviews...).

- To participate in and/or organise regular knowledge exchange activities between researchers and non-scientific key actors (invited talks by non-scientific key actors, visits to associations, NGOs, etc.).
- To designate persons responsible for communication with the public and provide their contact information on the institute's website and/or other communication channels.
- To include and regularly update on the Institute's website and/or disseminate on its social media good practice examples of non-scientific key actors engagement with the IIS.

3.7.3. Indicators

Order of priority	Indicator
1	Number of active participations in science cafés, science festivals or European Researchers' Nights.
2	Number of open days organised by the IIS.
3	Number of public lectures organised by the institute, involving and/or empowering different non-scientific key actors.
4	Number of press releases on research results.
5	The institute has designated staff as public contact persons (e.g. with details on the website).
6	Examples of good practice of non-scientific key actors engagement are regularly updated on the institute's website.
7	Number of lectures, presentations, participations, etc. by guests of external organisations (associations, NGOs, companies, etc.).

7.3.4.7. Timeline

(See Appendix IV)

3.5. Primary Outcomes

3.5.1. Strategic objective

The involvement of non-scientific key actors in the production of research outputs such as publications, tools and/or other products.

3.5.2. Recommended actions

- To encourage co-production with non-scientific key actors through various measures, such as including it as an evaluation criterion for awards or as a recommended activity for research groups.
- To encourage the publication of articles, materials and/or other types of tools (e.g. dissemination articles, interactive research results websites, patient support materials...) through different actions such as including them as evaluation criteria for awards or recommended activities for research groups.
- To identify the portfolio of research products and results of potential interest to institutions and companies.

3.5.3. Indicators

Order of priority	Indicator
1	Number of scientific publications in collaboration with external non-scientific organisations (industry, NGOs, patients, civil society, etc.) in which non-scientific actors are signed as authors or mentioned in the acknowledgements.
2	Publications, materials and/or tools aimed at different non-scientific key actors.

3.5.4. Timeline

(See Appendix IV)

4. MOTIVATION AND SATISFACTION OF NON-SCIENTIFIC KEY ACTORS

In addition to the different levels of participation discussed above, indicators have been identified to assess the motivation and satisfaction of research staff to involve non-scientific key actors at the different levels of participation, as well as to assess the satisfaction of non-scientific key actors' expectations following their participation in public participation processes.

4.1. Strategic objectives.

- To motivate and encourage research staff to involve non-scientific key actors at different levels of participation.
- To regularly assess the satisfaction of non-scientific key actors' expectations following their participation in public participation processes and identify actions for improvement.

4.2. Recommended actions

- To establish and/or maintain incentives for researchers or mechanisms for official recognition of participation in public participation processes (e.g. including awards or other recognition as a criterion for assessing the activities of research groups).
- To establish and maintain a system for assessing the satisfaction of non-scientific key actors, such as an annual survey, contact form, suggestion box, etc.
- To feed back non-scientific key actors satisfaction to the research staff involved, suggesting improvements to the process where appropriate (e.g. process to be carried out by staff dedicated to non-scientific key actors engagement as a specific part of their work).

4.3. Indicators

Order of priority	Indicator
1	The institute has incentives for researchers or mechanisms for official recognition of participation in public participation processes.
2	The institute has an annual system for assessing and improving the satisfaction of non-scientific key actors.

4.4. Timeline

(See Appendix IV)

GENERAL RECOMMENDATIONS FOR THE INSTITUTE OF HEALTH CARLOS III

Given that one of the objectives of the new Law on Science is to promote the active participation of the private sector and civil society in research, development and innovation, as well as the social recognition of science through the scientific education of society, the dissemination of scientific and technological knowledge, the participation of citizens in scientific decision-making and the recognition of innovative and entrepreneurial activities, the following recommendations are proposed:

- To encourage initiatives aimed at facilitating free access to data generated by research, developing open infrastructures and platforms, and promoting open participation of civil society in scientific processes.
- In the field of scientific and technological culture, to promote the participation of citizens in the scientific and technological process through the definition of research agendas, monitoring, data collection and processing, and other processes of citizen participation, as well as access to the culture of science and innovation for groups with greater barriers to access due to socio-economic, territorial and age or other factors.
- To develop the role and structure of the "Non-Scientific Key Actors" Participation Officer and the "Non-Scientific Key Actors" Participation Unit within the IIS, as well as a set of rules for the participation of "Non-Scientific Key Actors".
- The organisation of a biennial inter-institutional day for the participation of non-scientific key actors.
- Actions aimed at disseminating the policy of participation of "Non-Scientific Key Actors" in the ISCIII.
- The development of scientific incentives for IIS that excel in the participation of Non-Scientific Key Actors.
- The mentoring of IIS with no experience in the participation of 'Non-Scientific Key Actors'.
- To improve the scientific and innovative education and culture of society, so that everyone can acquire more scientific knowledge, understand the processes and nature of science and its relationship with society, interpret scientific information and have their own criteria for the changes taking place in their natural and technological environment.

Integration of the Scientific Activities of the Research Groups Attached to the Health Research Institutes Economic Management

GT4. *Institute Partnership*. 2022

Coordination: IDIBAPS

Manager: Dr. Elias Campo Güerri. Scientific Director

Executive Summary

The purpose of this report is to integrate the economic management of the worldwide scientific activities of the research groups affiliated to the IIS. The aim has been to obtain a guide of recommendations to advance this integration by defining actions to overcome the existing limitations.

Economic integration is understood to mean that the IIS management body manages all possible financial support received by the research staff coming from the IIS member organisations and attached to the IIS. This definition therefore takes into account the limitations inherent in the eligibility of the institutions established in the calls for proposals or other situations where the potential benefits may be reduced depending on the institution managing the support.

In order to analyse the current state of play, a 9-question survey was carried out on aspects related to management integration, including possible limitations and suggestions for improvement.

The results obtained in the 10 IIS surveyed, which include 52 different institutions, depend to a large extent on: a) the composition of the IIS themselves (hospitals, primary care centres, research centres, universities, CSIC or others); b) whether the centres that make up the IIS have a separate management entity from the one that manages the IIS; c) whether there is a formal and integral management agreement between the entities that make up the IIS (and not only with regard to indirect costs); and d) the type of economic resources (competitive, non-competitive, etc.) generated by the research groups.

The main conclusion of this analysis is that full integration is an objective that not all IIS will be able to achieve, given their own organisational structures and the fact that the associated entities retain their legal personality independently of the IIS. Annual improvement in this area should be an objective in itself, always taking into account the possibilities offered by the R&D ecosystem itself. To this end, the group proposes 8 recommendations to the IIS in order to improve their level of integration in the economic management of the global scientific activities of the research groups associated with the IIS.

Introduction

The aim of the Space for Stable Cooperation and Joint Work of the accredited IIS in the Partnership is to respond to the needs of the IIS, to guide scientific policies by aligning them with European strategic lines, and to promote cooperation between IIS and their participation in the definition of the ISCIII's lines of action.

To this end, the ISCIII has organised several working groups in 2022 and, in particular, the field of action of Working Group 4 (hereinafter referred to as GT4) corresponds to the integration of the economic management of the scientific activities of the research groups affiliated to the IIS.

Its main objective is to obtain a guide of recommendations for progress in the integration of management in order to establish criteria for monitoring the level of integration in the economic management of the funds raised by the research groups affiliated to the IIS, regardless of the institutions to which they belong, and to propose actions to overcome the existing barriers to effective integration.

Theoretical Framework

Firstly, it was essential to define what is meant by “economic integration” within the IIS in order to correctly diagnose the current situation and to be able to propose a guide of recommendations for improvement in this area, the ultimate objective of GT4.

Economic integration is understood to mean that the IIS management body manages all possible financial support received by the research staff coming from the IIS member organisations and attached to the IIS.

In fact, the reference to "all possible support" is precisely because there are limitations or specificities imposed by the funding agencies themselves. It is therefore considered as a universe of possible projects to be managed within the IIS:

- Those for which the IIS/managing unit is eligible to apply for such grants. Thus, grants that can only be applied for by entities such as universities, OPIS, CIBER intramurals, etc. are not included.
- Those in which applying through the IIS/managing body does not prejudice or condition the possibility of obtaining funding. Thus, grants applied for through other entities for very specific reasons, such as quotas or limits per entity and always with the express authorisation of the IIS management, would not be counted. For example: ICIs requested by CIBER.

Possible financial support includes all types of funding, both competitive and non-competitive: research projects, support for the recruitment of staff, donations, patronage, agreements with companies, support for innovation, etc.

Methodology

GT4 met on several occasions to discuss together aspects related to the economic integration of IIS (definition of the concept, identification of problems, limitations, analysis of cases, etc.), the working methodology to be followed during the working period and the content of the Recommendation Guide presented in this document.

One of the main working premises of GT4 was to assess that the survey to be proposed should not include information or data that the IIS already routinely provide to the ISCIII through the annual monitoring indicators. Finally, after the first working meetings of GT4, the coordinating body proposed a survey with 9 questions, including:

- Composition of each IIS: questions 1 and 2
- Current situation with regard to aspects that may affect economic integration within the IIS: questions 3 to 8
- Suggestions for improving economic integration within the IIS: question 9.

GT4 decided to send this survey only to the members of the group, as they were considered to be sufficiently representative, so a total of 10 surveys were completed.

The responses from each IIS have been integrated into a single database in order to analyse the results together. In case of doubt, the data were checked with the IIS and, occasionally, some remaining information was completed and could be checked online (e.g. identification of the managing body of the IIS). It should be noted that there are no differences in the interpretation of the questions by the different respondents.

Development and Results

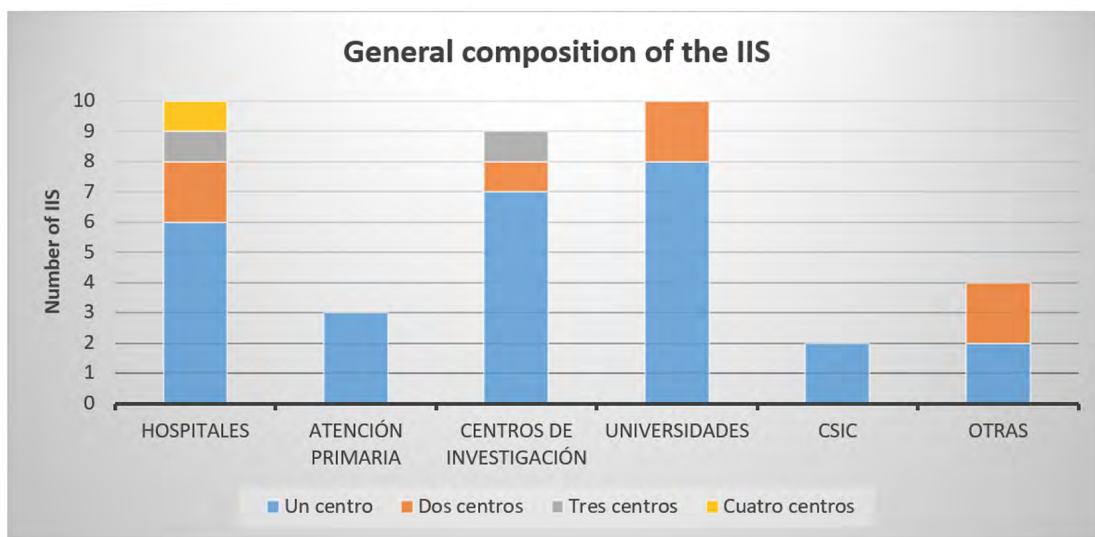
The results obtained in the survey questions (APPENDIX II) 2 to 8 are analysed below.

Question 1 concerns the identification of each IIS and the contact details of the person responsible for completing the survey in case of queries. Question 9 will be analysed in the following section, which is devoted exclusively to the guide to improving economic integration within the IIS.

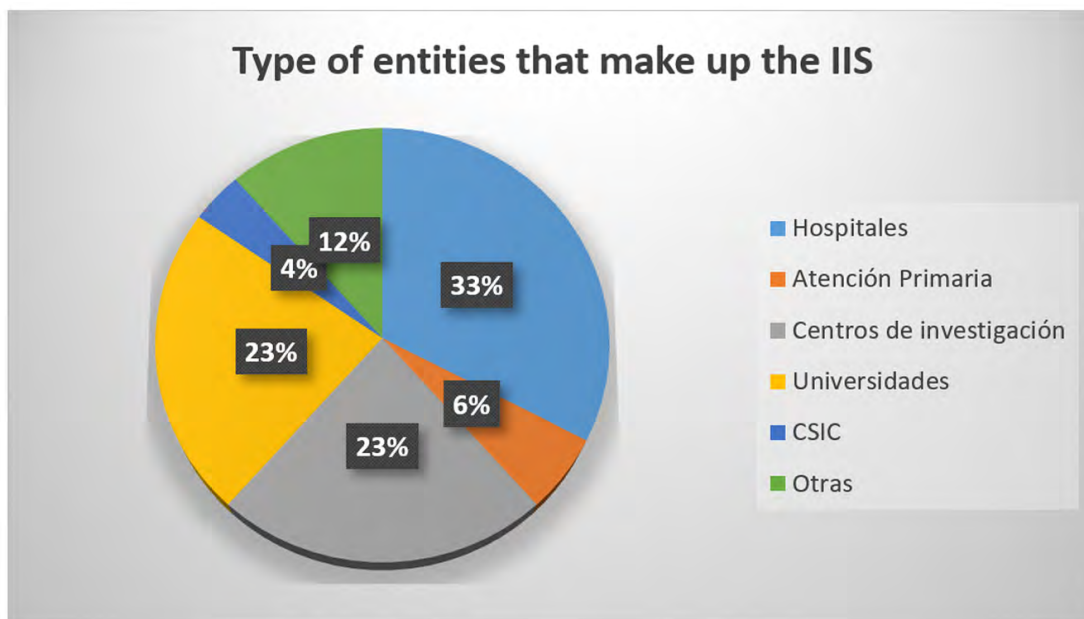
It is important to bear in mind that the 10 IIS surveyed are made up of 52 different institutions and that for most questions the unit of reference is the partner institutions.

Question No. 2: Identification and categorisation of the partner entities that are part of your IIS. Identification of the managing entity of the IIS

Following the natural structure of IIS, the 10 IIS surveyed have at least one hospital and one university. In addition, 3 IIS have specific primary care centres. For the purposes of this survey, care units that are both hospital and primary care have been counted as “hospitals”. In addition, there are 9 IIS that have at least one research centre, 2 IIS that have a CSIC centre and 4 that have other types of centres in their composition.



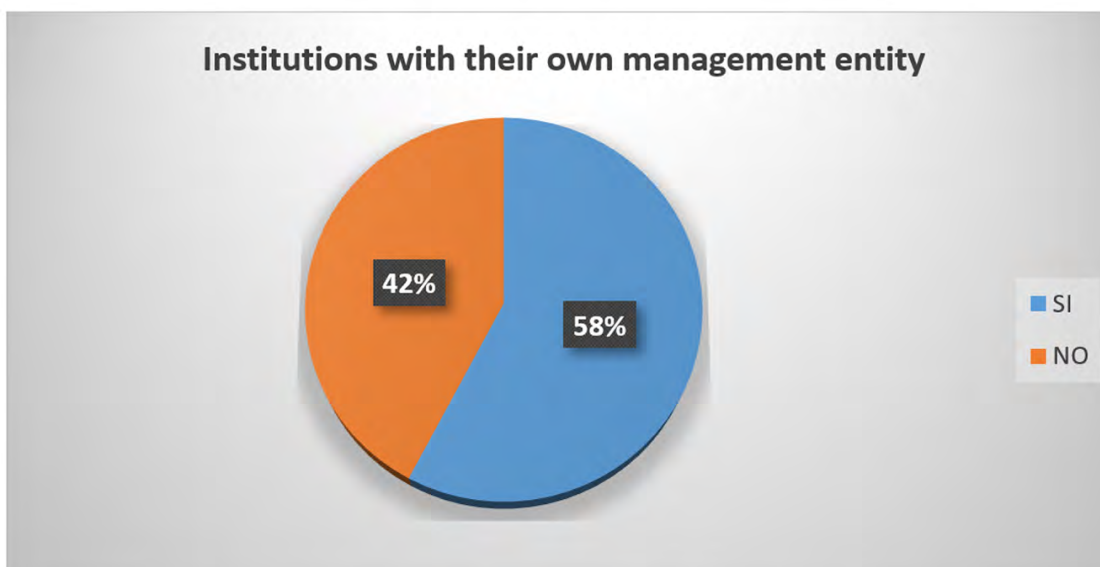
On the other hand, the IIS that responded to the survey are made up of between 3 and 9 different institutions, with a total of 52 units belonging to the different fields mentioned above.



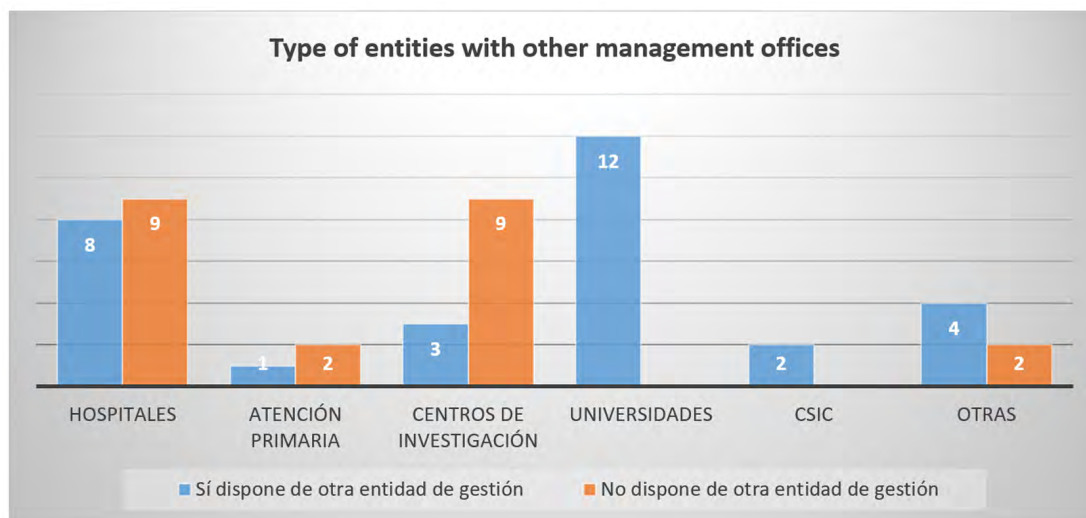
39% of the centres belong to the care sector, either hospitals (33%) or primary care (6%). Foundations/ research centres and universities each account for 23%, while the CSIC accounts for 4%. Finally, the remaining 12% correspond to institutions belonging to the state public sector (regional systems, health departments, etc.).

Question No. 3: For each of the individual entities that are part of your IIS, do these entities have a different management entity through which projects are managed?

Of the 52 institutions that are part of the 10 IIS surveyed, 30 (58%) have their own management entity that is different from the one managing the IIS.

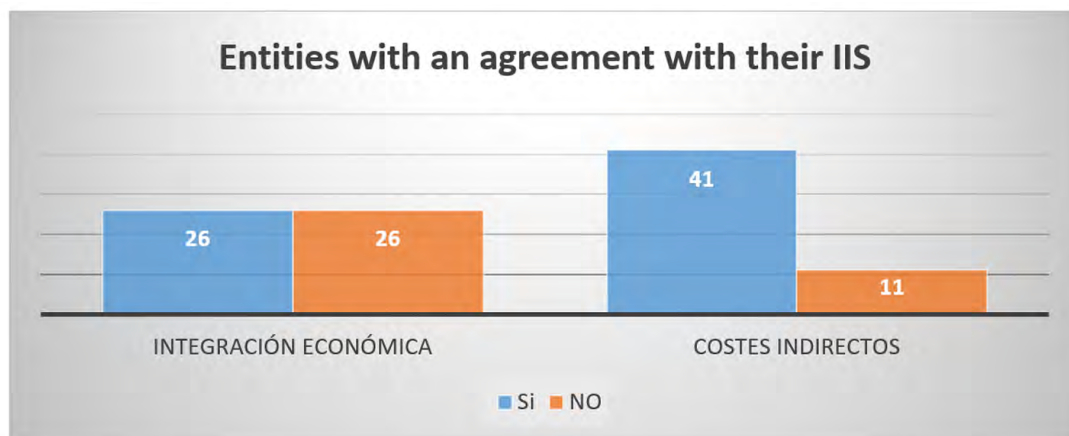


An analysis of the data by type of institution shows that the universities and the CSIC all have an alternative management body, mainly because they were entities with independent legal personality before the IIS were set up. In the case of other entities, it is more common to have another management unit. However, in the group of hospitals, primary care and research centres, it is more common not to have an alternative management entity.



Question No. 4: Does your IIS have a full economic integration agreement with the institutions that are part of it? In other words, does it have an agreement for all research staff to apply for all possible grants or sources of income (according to the initial definition of the survey) through the managing entity of the IIS?

This question aims to establish the extent to which the economic integration of the IIS is formalised with respect to the institutions that make up the IIS. It also asks whether there is an agreement on the sharing of the indirect costs of the funds managed. In total, 41 institutions (79%) have a signed agreement with their IIS for the sharing of indirect costs, while only 26 (50%) have an agreement for full financial integration.



However, when analysing the types of institutions with which these agreements have been formalised (see table below), it can be seen that research centres and care institutions are the most likely to have an economic integration agreement (69% on average). In contrast, universities, CSIC and other entities have a significantly lower ratio (20% on average).

With regard to indirect cost agreements, all the research centres replied that they have an agreement, mainly because they are the only IIS centre, but even if there is more than one, they also have an indirect cost agreement. The case of the CSIC stands out with 100%, but as it only refers to two institutions, it is difficult to make a clear diagnosis as to whether this is a generalised strategy for all IS that have CSIC. It is worth noting that 82% of hospital institutions have an agreement on indirect costs, while universities and CSIC have an agreement in two thirds of cases.

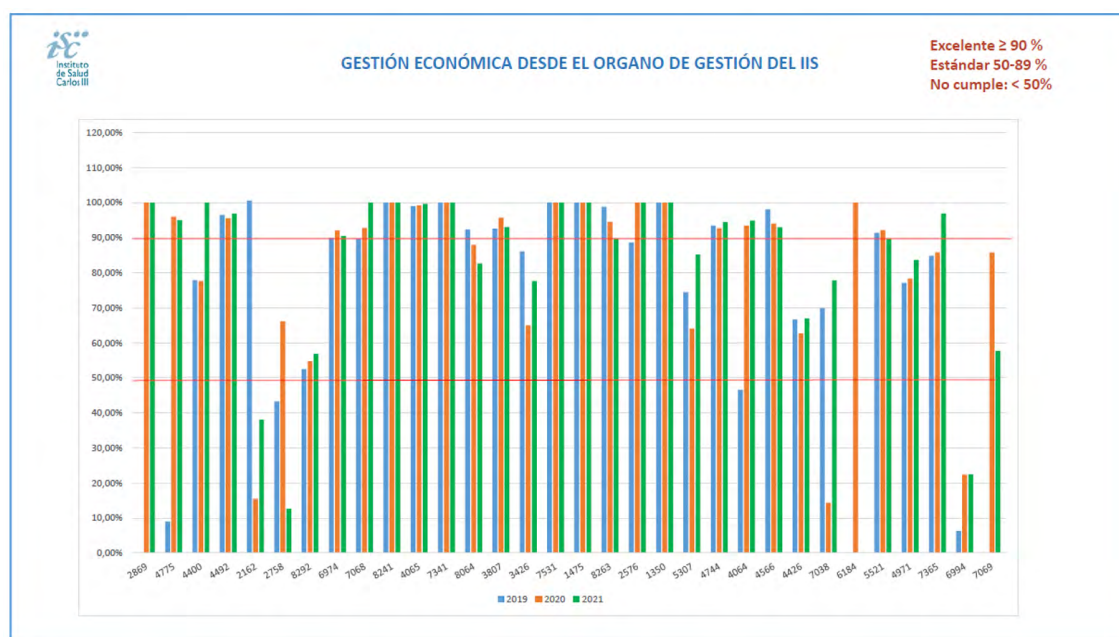
	No. of institutions	Economic integration agreement in place	Indirect cost agreement in place		
Hospitals	17	11	65%	14	82%
Primary Care	3	2	67%	1	33%
Research centres	12	9	75%	12	100%
Universities	12	2	17%	8	67%
CSIC	2	0	0%	2	100%
Other	6	2	33%	4	67%
TOTAL	52	26	50%	41	79%

However, it is important to highlight that, although these agreements are formalised, in some cases they are not in place or are in the process of being implemented, are not applied systematically or are limited to a specific aspect (clinical trials, specific staff, etc.).

Question No. 5: How do you perceive the level of economic integration by entities that make up your IIS, considering the initial definition?

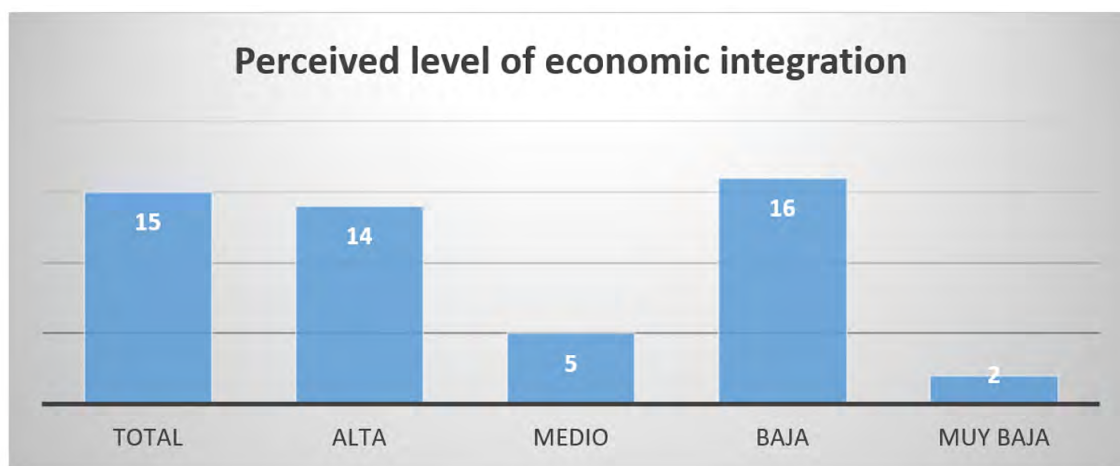
In the annual monitoring indicators of the IIS, each centre fills in the indicator "Economic management by the management body of the IIS", which aims to assess the percentage of funds raised by the research groups affiliated to the IIS and managed by the management body, in relation to the total funds obtained by the research groups of the IIS.

In an exercise of verification and homogenisation, the ISCIII itself shared the general results reported by the 31 IIS for this indicator over the last 3 years:



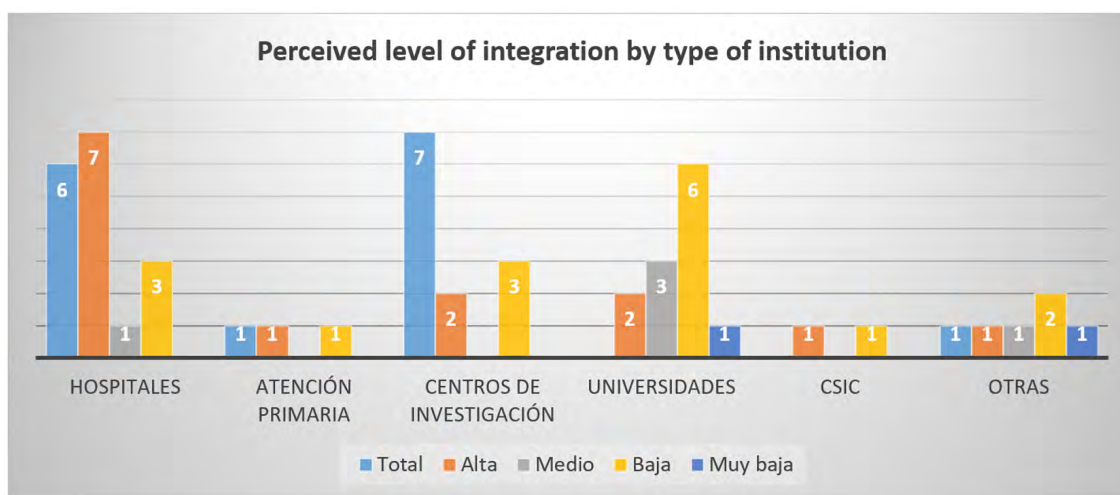
The results for this indicator are very significant, with 12 IIS reporting 100% in some annual period and 23 IIS reporting more than 90% in some annual period. Leaving aside the possible interpretations or methods of calculation of this indicator by each IIS, it was suggested in the GT4 working sessions that the perceived economic integration was far from reaching these levels.

It was therefore decided to consult on the perceived level of economic integration of the different institutions that make up each IIS. According to the IIS surveyed, they consider themselves to be fully or very highly integrated with 29 institutions (56%), while they consider themselves to be less or very less integrated with 18 institutions (35%).



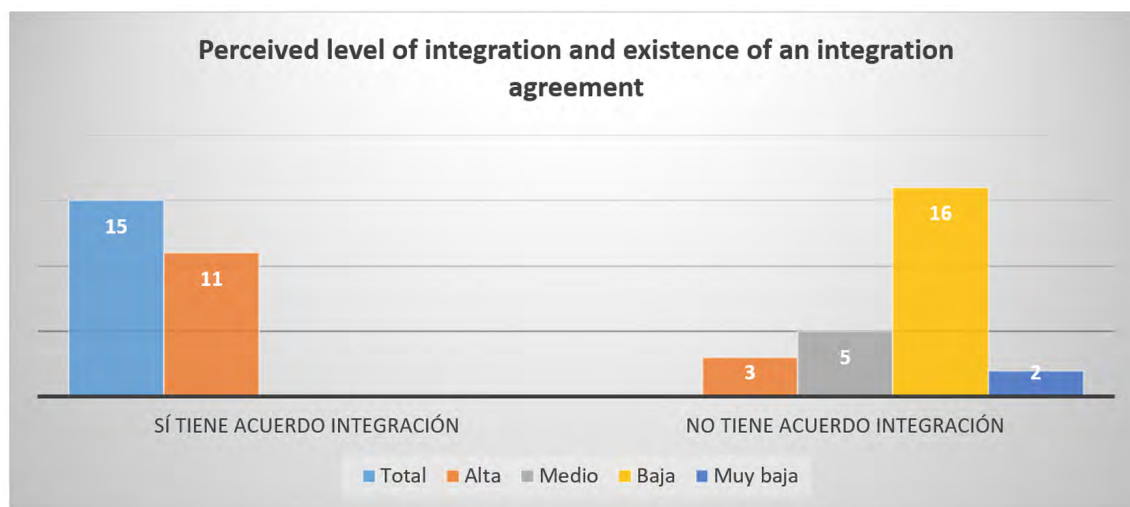
We now turn to analyse these data in more detail:

By type of institution



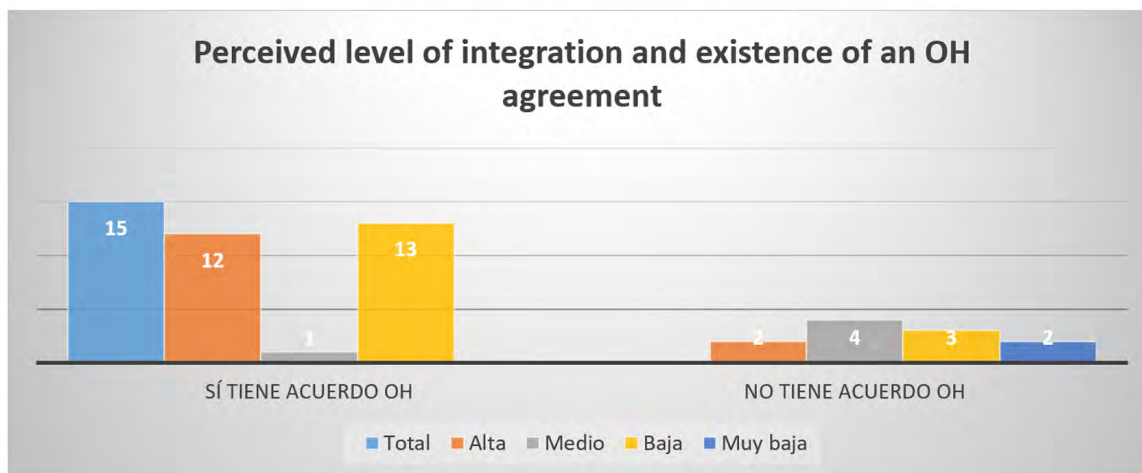
Hospitals and research centres have a higher perceived level of economic integration, while universities and other types of centres have a lower or even very low level. Primary care centres and CSIC seem to be more dependent on the ecosystem of the specific IIS to which they belong.

By existence of an economic integration agreement



In this case, the existence of an economic integration agreement directly correlates with a high or total perception of integration, while the absence of such an agreement generates a particularly low level of perceived integration.

By existence of an agreement on indirect costs

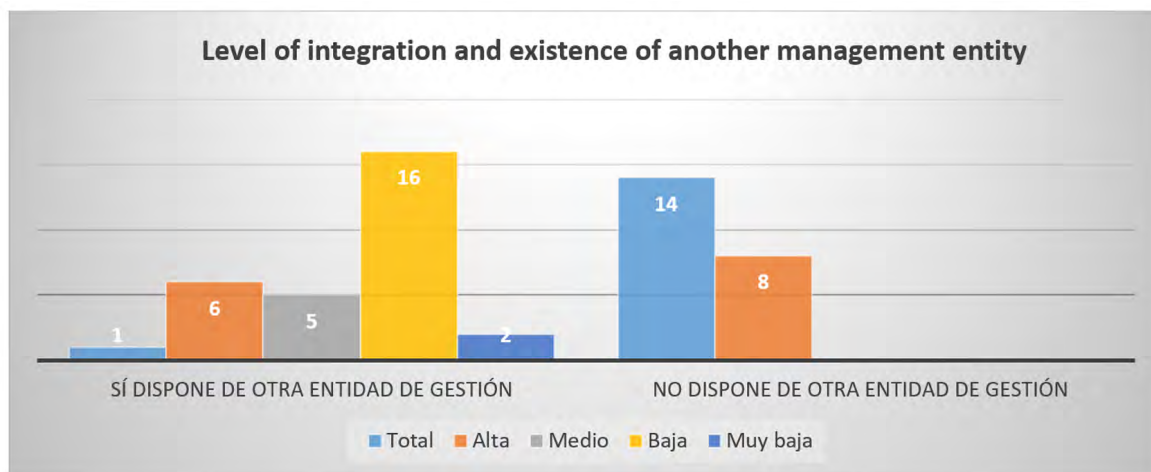


In contrast to the previous one, there does not appear to be a correlation between the existence of an agreement on indirect cost sharing and the level of perceived integration. In fact, some IIS report that despite having an indirect cost sharing agreement, integration remains low.

Specifically, of the 18 centres that reported a low or very low level of integration, none have an economic integration agreement. And although 13 of them have an agreement on indirect cost sharing, this does not improve their perceived level of economic integration. However, question 6 explores this specific issue of indirect costs in more detail.

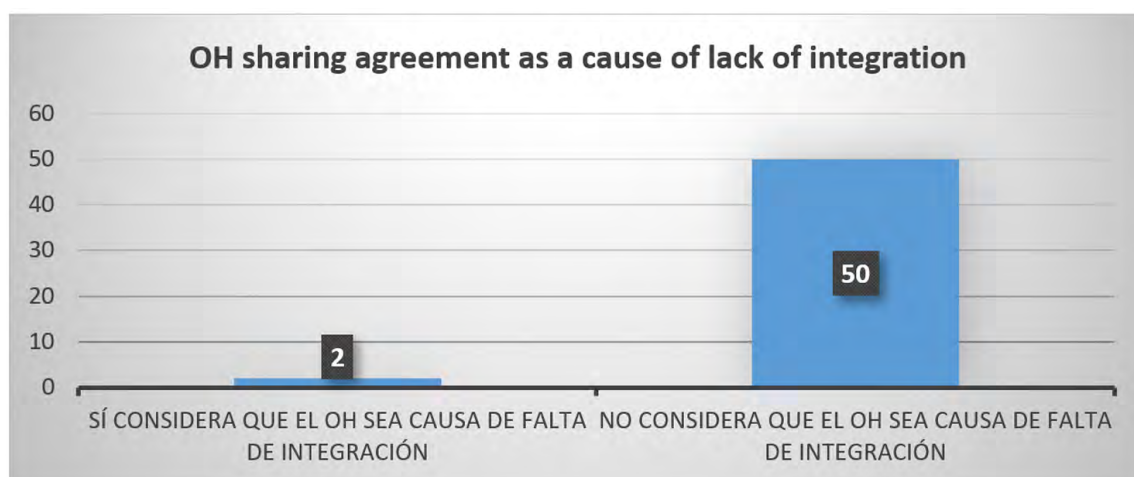
By whether there is another specific management entity

Following on from the results of question 3 regarding the existence of other specific management entities, the level of perceived integration is significantly correlated with whether or not there is another management entity, such that those who have no alternative have a higher level of perceived integration. In contrast, those who have an alternative entity are perceived to have a lower level of integration.



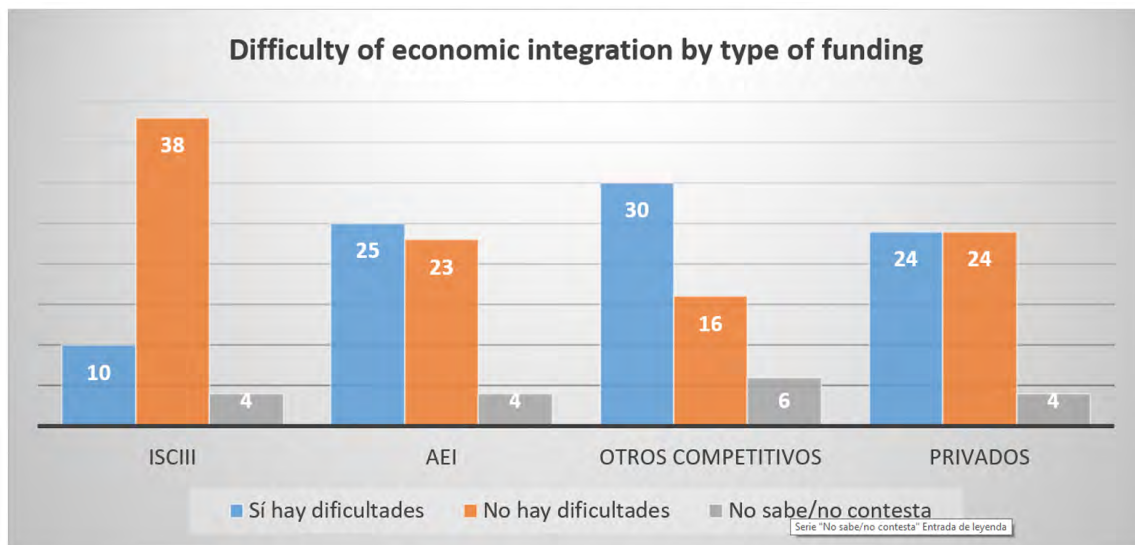
Question No. 6: In the case of integration problems, please indicate for each entity whether the specific problem is due to the absence or non-application of an indirect cost sharing agreement with the entities.

In response to this question, IIS overwhelmingly report that their economic integration problems with their partner institutions are not due to an indirect cost sharing agreement. Only two centres are identified as having integration problems due to indirect costs.



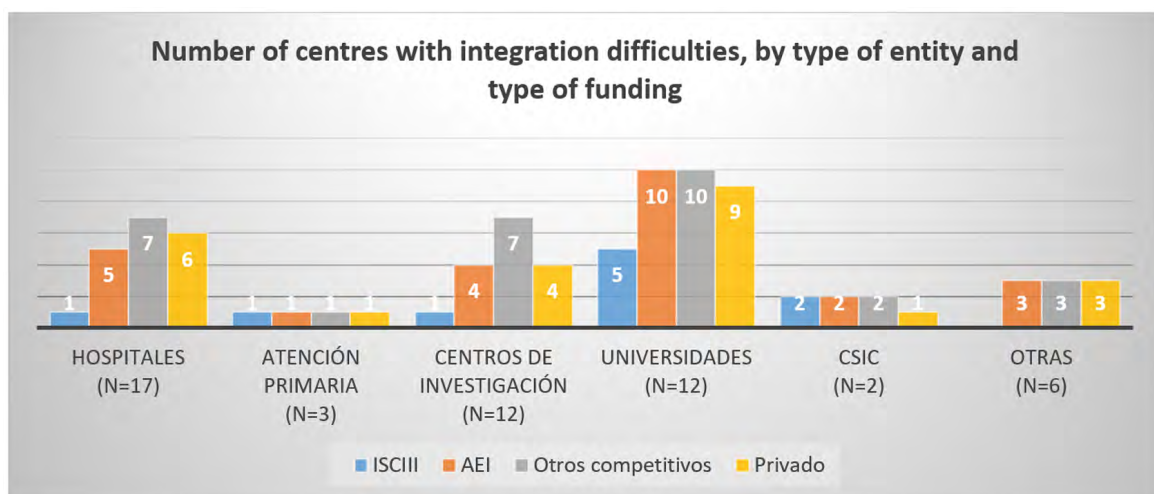
Question No. 7: In the case of integration problems, please identify for each entity whether the problem is by type of funding.

The purpose of this question is to analyse whether the type of funding in question (competitive or non-competitive, and according to the funder) has any impact on the lack of integration.



According to the data obtained in the survey, with the exception of the funding received by the ISCI, there are difficulties for the IIS to manage the funding of the groups when the funding agencies are other competitive bodies, the State Research Agency and the private sector.

Respondents reported that if the funder does not require applications to be processed by the IIS, they are more easily processed by the entities of origin. In addition, there are limitations or requirements in terms of employment relationships, either directly by the funding bodies or through the need to allocate own staff time. It is also mentioned that some universities only allow grant applications through the IIS if this is the only way to access these calls. Another argument is to select which calls are easier (in terms of scoring/assessment) to access through the IIS or through the home institution and to choose accordingly. Reference is also made to the internal policies of the entities of origin or even to industrial and intellectual property, especially in the case of private sector funding. Finally, aspects related to the calculation of merit are mentioned in such a way that, when processed by the IIS, they are not calculated at the curricular level in the entity of origin, which penalises researchers.



This graph shows the number of entities reporting integration difficulties by type of funding and by type of entity. In general, hospital entities and research centres, both with a very similar pattern, tend to have fewer difficulties when it comes to the ISCIII, but they increase with the rest of the funding agencies or sponsors.

In the case of universities, as in the previous cases, there are fewer difficulties when the funding entity is the ISCIII, but they increase significantly with the other funding agencies. With regard to the CSIC, and considering that there are only 2 participating centres out of 52, difficulties are reported in all types of funding agencies/sponsors. Finally, as regards primary care and other entities, around one third to one half of the possible cases are reported.

Question No. 8: In the case of integration problems, please identify for each entity whether there are other economic integration problems.

With the exception of specific cases, the following reasons are generally given by the IIS as causes of economic integration problems within their IIS:

- Failure of the institution of origin and/or IIS leadership to promote economic integration.
- Difficulties in the assignment of research staff from the centres of origin to the IIS.
- Lack of agreement with one (or more) of the entities making up the IIS.
- Lack of agreement in certain sections or areas (European projects, intellectual and industrial property, etc.).
- The entities of origin consider that their indicators are decreasing or that their national or international rankings may be lowered, which may have a direct impact on the funding they receive from their Autonomous Community, especially in the case of universities.

Furthermore, based on the results of the survey, it can be said that the absence of a specific agreement on economic integration (with or without indirect cost sharing) significantly reduces economic integration.

Conclusions and Suggestions

It is important to bear in mind that full integration is an aspiration that not all IIS will be able to achieve, given their own organisational structures and the fact that the associated entities retain their legal personality independently of the IIS. Annual improvement should be an objective in itself, always taking into account the possibilities offered by the R&D ecosystem.

In order to improve the economic integration of the IIS with regard to the entities that make up them, the following recommendations are made:

1. To encourage all institutions associated with the IIS and/or the representation of their research staff to be involved in the governance of the IIS. This governance should be understood in a broad sense and could be any decision-making or consultative body of the IIS.
2. To promote the figure of the IIS through all associated entities and/or the representation of their research staff as a management reference tool and not just as a tool to obtain certain funding.
3. To highlight the value of the management carried out in the IIS, which offers a complete, close and efficient service to the research staff, who can see the simplification of the management processes

compared to other larger institutions (universities or CSIC), reducing the time spent on administrative matters and increasing the time devoted to R&D.

4. The funding agencies (ISCIII/AEI...) should promote, encourage or even oblige the processing of applications through the IIS management entity, including possible modifications to the call rules to facilitate this as much as possible. In the case of the ISCIII, the efforts made by the ISCIII in 2022 towards this obligatory nature in health R&D projects are acknowledged. However, it would be necessary to open a debate on certain structures that directly affect the economic management integrity of the IIS, such as the CIBER (especially when it comes to international funds).
5. Funding, assessment or governmental liability agencies should recognise/calculate the merits that IIS brings to the entities of origin, be it for institutional accreditation, rankings, annual structural budget sharing, etc.
6. An indirect cost-sharing agreement between institutions does not seem to facilitate integration per se, but it can be an incentive for it. Therefore, it is not advisable to have only an indirect cost-sharing agreement without the support of a strategic agreement on economic integration.
7. Each IIS should define and negotiate with its constituent entities the objective of possible economic integration and reflect it in an effective economic integration agreement, with or without indirect cost sharing between the institutions. This effective economic integration agreement may cover the following areas:
 - a. Research: definition of grant dimensions that determine which applications are processed by the IIS and which are processed by the centre of origin. These dimensions can be: type of funder, specific calls that are mandatory for the IIS and others that are optional, topic related to biomedicine or translational research, etc. These decisions may be influenced by certain legal or regulatory aspects of the calls (own staff, etc.).
 - b. Infrastructures and scientific-technical services: specification of common services or contributions.
 - c. Spaces/Resources: distribution of the resources of the IIS and associated entities for the research groups to carry out their R&D activities.
 - d. Employment/scientific promotion: employment positions in the entities of origin to be transferred or managed by the IIS, negotiation of salary supplements for assigned research staff, shared or harmonised career paths, etc.
 - e. Recognition of merits: the associated entities must recognise the merits obtained by their research staff (especially young researchers) through the IIS, both in terms of curricula and the distribution of structural budgets of the entities of origin.
 - f. Management of intellectual and industrial property and of new projects based on this pre-existing IPR.
 - g. Information: establishment of the bidirectional channels and periodicity for sharing information, indicators, etc. generated by the research staff assigned to the IIS with the entities of origin.
 - h. Multi-institutional affiliation in the R&D output of all research staff belonging to the IIS, so that each researcher, regardless of his or her entity of origin, can include in his or her affiliation all IIS-affiliated institutions.

- i. Management models with the associated entities: negotiation of new models, such as the integration of the management members of the latter with those of the IIS, under IIS-led governance. These models would allow ownership of certain projects to remain with the entities of origin, but management would be on the IIS.

Finally, in order to monitor this improvement in the economic integration of the IIS, it would be necessary to have at least one indicator that directly and accurately reflects the evolution. This indicator or indicators should be jointly analysed and agreed by the IIS and the ISCIII, including the method of calculation and the criteria for inclusion or exclusion.

Integration of Primary Care in Health Research Institutes

GT5. *Institute Partnership. Primary Care 2022.*

Coordination: IDISBA

Manager: Dr. Joan Llobera and Dr. Oana Bulilete (IDISBA-GAP Mallorca)

Executive Summary

The Health Research Institutes (IIS) Partnership on the initiative of the ISCIII, organises working groups each year to reflect and make proposals on relevant issues prioritised by the IIS themselves. The aim is to gain a better understanding of the issues affecting IIS, to collect examples of good practice and to make strategic proposals for improvement.

The current IIS accreditation decree, published in 2016, specifically mentions PC, indicating that the centres in the area of influence of the hospital that serves as the core of the IIS are integrated into the IIS1. The IIS are subject to an annual monitoring process, in which two of the monitored indicators make specific reference to primary care (PC), specifically to the role of PC in the IIS, assessing the level of participation of researchers and the availability of spaces dedicated to their research activities in PC centres.

In 2022, one of the Partnership's working groups focused on analysing the situation of Primary Care (PC) research in the IIS and offering strategies to promote the integration of PC research in them. Coordinated by the IIS of the Balearic Islands (IdISBa), members of 10 other IIS participated.

The working group's objectives were to find out the real level of collaboration of PC participation in the IIS, to identify good practices of the IIS in PC, and to carry out a SWOT analysis in order to define strategic lines and actions aimed at integrating PC researchers into the groups and research areas of each IIS.

For this purpose, an online questionnaire (Appendix 1) was developed, the content of which was agreed among the members of the GT-AP Partnership and extended to the rest of the IIS. The survey took place between July and September 2022. Twenty-nine of the 34 IIS responded.

Among the results, only 1/3 of the IIS explicitly include PC as a constituent part of the IIS. Participation in governance bodies is scarce: in 1/3 of IIS there is PC representation on the management/executive committee, while in almost 60% of cases there is a PC member on the internal scientific committee (in 1/3 of IIS the PC leads a scientific area or programme), but the presence of PC researchers on the external scientific committee is anecdotal.

In more than 1/3 of the IIS there is no PC research group and in the rest there are between one and three groups. On the other hand, PC researchers collaborate in an average of 10% of ISS groups. There is an average of 34 PC researchers per IIS, in 20 out of 29 IIS they represent less than 5% of the total number of researchers in the IIS. In no case the level of excellence set by the ISCIII of 10% of PC researchers is exceeded. Only 1/3 of the IIS have 5 or more active competitive PC projects. One in three institutes has some kind of support structure for research in PC centres.

One third of the IIS have some role for PC, generally the same as those reporting good practice in PC. The SWOT analysis suggests some opportunities arising from being the one who generates essential population-based clinical databases for research in large health databases, and that telematic solutions for meetings and group work reduce the disadvantages of PC dispersion.

Five lines of improvement were proposed: i) Strengthening the role of PC in the governance structures of the ISS, with 5 actions. ii) Promoting the participation of PC researchers in the IIS, with 7 proposed actions. iii) Promoting research at primary level, with 7 actions. iv) Disseminating the IIS among PC professionals, with 4 proposed actions. v) Promoting the social dissemination of PC research, with 7 actions.

In conclusion, with regard to the role of PC in IIS, only one third of IIS have a significant presence of PC, another third has little, and in the rest is anecdotal or non-existent. There is therefore much room for improvement; it is a challenge that the IIS must meet and that the Partnership and the ISCIII itself cannot avoid. The report can serve as a basis for knowledge of the reality, suggestions for good practice and a significant volume of actions to be developed to reverse this unfavourable situation.

Introduction

Health Research Institutes (IIS) are based at a university hospital (with a medical faculty and teaching units in most medical specialties) and must have their headquarters in a large physical space within or adjacent to the hospital, although there may be other laboratories or units within the organisations that make up the IIS. The IIS must be composed of at least one public health centre and one public university, but may also include other universities, research centres, municipal institutions, companies and other institutions with health research activities. The current IIS accreditation decree¹ specifically indicates that the PC at the centres in the area of influence of the hospital that serves as the core of the IIS be integrated into the IIS. The IIS are subject to an annual monitoring process by the ISCIII and must undergo a re-accreditation process every 5 years². Two of the monitored indicators relate to PC in the IIS, assessing the level of participation of researchers and the availability of space for their research activities in at least one health centre.

PC has always played a smaller role than expected in terms of labour or budgetary weight (27% of the the medical staff of the National Health System [NHS] are from PC and 19% are nurses, accounting for 14% of public health expenditure)³, due to its specific characteristics of dispersion of professionals, its historical distance from "academia", the lack of support structures and the pressure of care that prevents working time devoted to research.

PC is made up of professionals in medicine and family and community nursing, paediatrics, midwifery, physiotherapy, mental health, pharmacy, dentistry... PC incorporates a large number of young professionals with specialised training in the NHS, some of whom will develop a vocation for research, a potential that needs to be channelled appropriately, if possible, through the IIS.

The research landscape in PC is poor, its weight is much lower than expected given the weight of PC care. This can be seen in indicators such as the proportion of projects funded in the calls for Strategic Action on Health (AES), which usually does not exceed 4%, or the proportion of impact publications included in the Web of Science, although the difference between the Autonomous Communities is very significant⁴.

In order to have reliable information and to be able to know the PC research landscape by Autonomous Community, in 2023, the MAP of Research and Innovation in PC in Spain has been prepared, with data from 2022. It has been coordinated by ISCIII with the help of the Autonomous Communities. The map includes the resources allocated, existing support structures, census of researchers, competitive projects and scientific production this year. Primary Care Centres – WEX (arccgis.com)

The IIS Partnership, on the initiative of the ISCIII, organises working groups each year to reflect and make proposals on relevant issues prioritised by the IIS themselves, including examples of good practice and strategic proposals for improvement.

In 2022, this working group (GT5-AP) worked on strategies to advance the integration of PC research in the IIS. The specific objectives were to identify good practices of the IIS in PC and to carry out a SWOT analysis in order to define strategic lines and actions aimed at integrating PC researchers into the groups and research areas of each IIS.

We hope that the initiative will serve to gradually integrate PC researchers into the IIS, thus strengthening health research in Spain.

Theoretical Framework

According to the General Law on Health, the research function should accompany the health care and teaching function of the national health system in all areas of care, including PC. Both at national level and in regional health services, it is essential to support PC in the development of research in PC in order to provide new knowledge and useful evidence that can improve the efficacy, effectiveness and efficiency of health promotion interventions, the prevention and treatment of health problems and the organisation of health services, and ultimately to achieve the best health outcomes for patients and the community.

In daily practice, health professionals and the management of PC make many decisions for which they need useful and accurate information that research should provide: the possible causes of a given health problem and the associated risk factors, the most appropriate diagnostic strategies, the possible health promotion and prevention activities to be undertaken, the possible interventions and the most effective recommendations⁵.

Scientific societies, in particular the semFYC, have played an important role in promoting research on PC. At the European level, WONCA Europe and EGPRN (European General Practice Research Network) have developed the Research Agenda for General Practice/Family Medicine and Primary Health Care in Europe⁶, proposing a model for prioritising research in PC along four dimensions: i) clinical and related problems, ii) patient-centred approach, iii) community aspects (including equity and diversity), iv) organisational and management aspects.

It should not be forgotten that the knowledge generated must be applicable, and innovation (or knowledge transfer) seeks to translate this knowledge into improvements in the organisation of services, in the health of the community (social impact) and in the creation of new products and wealth (economic impact). The basis of innovation is therefore the organisational talent that makes it possible to transform this new knowledge produced by researchers into real improvements in existing services (improving the effectiveness and efficiency of health programmes and services, creating new activities, circuits or guidelines) or into new products on the market that generate wealth and health benefits (new technologies, new drugs, etc.)⁵.

To support research activities, in the early 1990s the ISCIII encouraged the creation of clinical-epidemiological, clinical-experimental and mixed research support units, articulated in the Network of Research Units, which spread throughout the NHS. By 1993 there were 110 units, of which 14 were dedicated to PC and a further 16 were shared with hospitals. Its stimulus waned, the network ceased to exist and only a few PC units survived; other mixed or clinical-epidemiological units formed the nucleus of many IIS⁷.

In 2002, the ISCIII regulated and financed the creation of the Thematic Networks for Cooperative Health Research (RETICS) and the Biomedical Research Networking Centres (CIBER), which brought together most of the health research groups that exceeded the activity thresholds required for their integration. 21 RETICS were created: one of them, the Research Network on Prevention and Health Promotion Activities (redIAPP),

was a specific PC network that brought together 12 groups from different Autonomous Communities. Despite the reduction in its funding in subsequent periods, it remained active and dramatically increased its research output⁸. Other PC groups focused on chronicity research were integrated into the Health Services Research and Chronic Patients Network (REDISSEC). Some PC researchers may have been hosted by other research groups in other RETICS or other CIBERs.

In 2021, the ISCIII launched a competitive call in the AES for the creation of Health Outcomes-Oriented Cooperative Research Networks (RICORS), defining four priority areas, one of which was PC research, with a focus on implementation research. In this call, one RICORS was presented, the Research Network on Chronicity, Primary Care and Health Promotion (RICAPPS), which brings together 26 research groups, many of which were already involved in RedIAPP and REDISSEC, with 395 researchers, most of them from PC, from 12 autonomous communities, in addition to 9 clinical care groups with 247 researchers. In general, the RICAPPS groups play a very prominent role and are considered to be highly competitive in the respective IIS in which are integrated.

The initiatives of the ISCIII to support the new RICORS call for proposals, the new accreditation indicators of the IIS that promote research in PC, and the promotion of the R&D&I actions of the Primary and Community Care Action Plan 2022-2023⁹ have been positively evaluated in PC.

The promotion of quality research in PC in Spain depends to a large extent on its link with the IIS. However, the basis for a competitive clinical research must involve the health services and the management of PC, which must integrate research into their actions as an essential pillar of PC; promote research lines that meet their planning and management needs; create support structures for research, providing space, equipment and methodological support staff; promote the training of researchers and the creation of research groups; facilitate the intensification of research professionals, create positions that combine care and research, and stimulate research by recognising it in the professional career. To this end, the PC departments, in addition to the IIS, should devote part of their budgets to promoting these research strategies.

Methodology

In order to respond to the objectives set out at the end of the introduction, in addition to an exhaustive collection of information on the situation of PC in the IIS by means of an ad hoc questionnaire, the working group set out to identify the best practices of the IIS in PC and to carry out a SWOT analysis, with the aim of defining strategic lines and actions aimed at the effective integration of these profiles in the research areas of each IIS.

To respond to these objectives, the actions carried out are described below.

An online questionnaire has been developed (Appendix 1), the content of which has been shared and discussed among the members of the GT-AP Partnership. It was subsequently extended to the rest of the IIS. The survey took place between July and September 2022. The questions were grouped into 4 main sections, which allowed the collection of identification data, affiliation data, analysis of the situation and identification of good clinical practices.

On the other hand, a SWOT analysis was carried out, with an initial proposal and two rounds of consensus among the members of the group.

Similarly, a series of strategic lines and actions to be carried out were defined on the basis of the information gathered in the questionnaire, the SWOT analysis and the contributions of the members.

Development and Results { XE "4. Results"}

The response rate was 85.3% (29/34 IIS) and the geographical distribution is shown in Figure 1.

Figure 1: Geographical distribution of participating IIS



The presence of PC in different councils or committees is presented in Table 1, with a notable presence of PC as a constituent entity in more than half of the IIS (65.5%, 19/29) or in internal scientific committees. However, a very low representation of PC was found in external scientific committees.

Table 1: Participation of PC in IIS structures

N=29	Yes	No	Mean
Present PC explicitly as a constituent entity	65.5%	34.5%	
PC representatives on the Management Board/Committee	34.5%	65.5%	
PC participation in internal scientific committee	58.6%	41.4%	0.8±0.9
PC participation in external scientific committee	6.9%	93.1%	0.1±0.3
PC participation in other committees (e.g. innovation, training, responsible research)	48.3%	51.7%	

The PC leadership of different scientific areas/programmes or research groups, as well as other aspects related to the IIS groups, are detailed in the following table.

Table 2: PC leadership and presence in IIS groups.

N=29	Yes	No	Mean
Scientific area/programme leadership*	34.5%	65.5%	
Groups led by PC+ researchers			1.3±2.0
Associated clinical group	69.0%	31.0%	
Associated clinical group mainly PC	20.7%	79.3%	

* areas: public health, epidemiology, health services, chronicity, ageing, chronic diseases, among others.

The results show the reduced leadership of areas or programmes by PC researchers, as well as the scarce presence of associated clinical groups composed mainly of PC professionals. On the other hand, the leadership of groups and the groups with PC researchers as collaborators are detailed in Figures 2 and 3.

Figure 2: Groups led by PC researchers

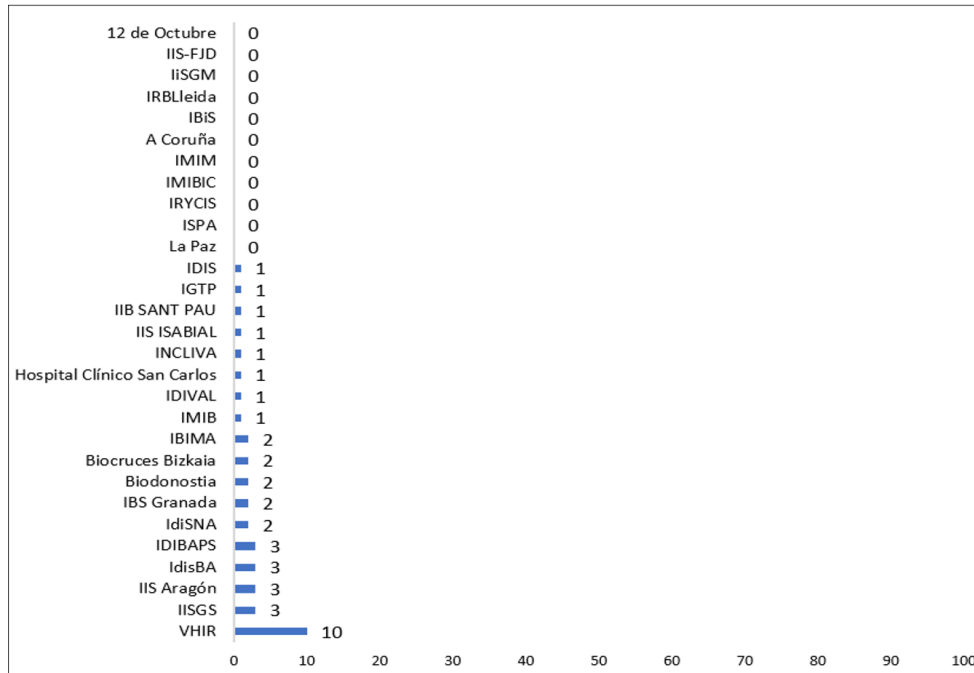
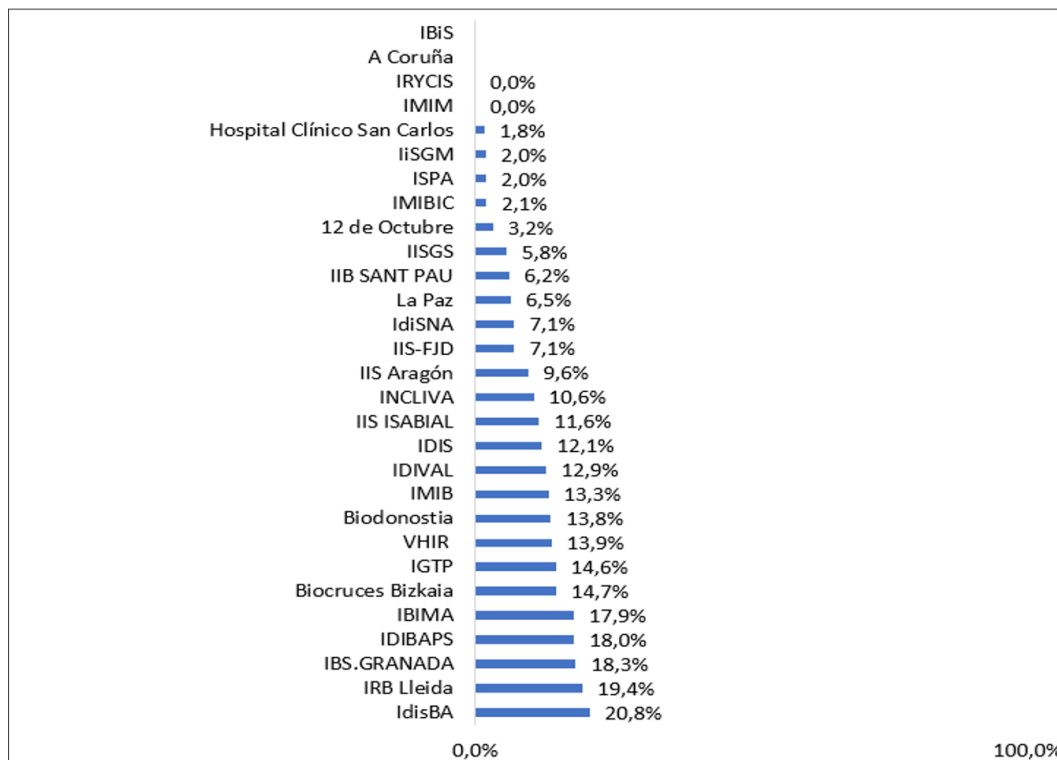


Figure 3: Groups with PC collaborators/Total groups



The groups in which PC researchers collaborate are from different thematic areas, as shown in the following figure.

Figure 4: Thematic areas of groups with collaborating PC researchers

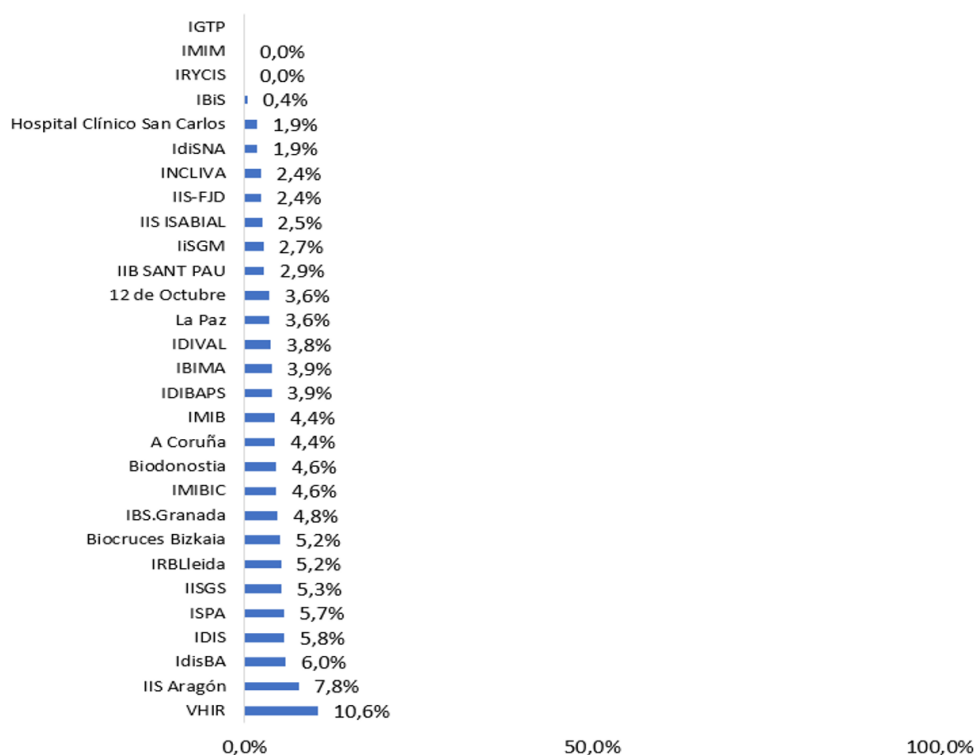


Aspects related to the figure of PC researchers are described below.

Table 3: Characteristics of PC researchers

N=29	Yes	No	Mean	
Total IIS researchers			832.4±264.5	
PC researchers			34.0±26.7	
Staff specifically contracted for PC	20.7%	79.3%	0.6±1.7	
IIS with presence of professional category among PC researchers and number	Medicine	69.0%	31.0%	25.0±25.9
	Nursing	55.2%	44.8%	5.6±3.5
	Statistics	10.3%	89.7%	2.0±1.7
	Pharmacy	31.0%	69.0%	2.3±1.4
	Psychology	20.7%	79.3%	3.2±1.9
	Other*	44.8%	55.2%	3.7±4.0

*Physiotherapy, biology, occupational therapy, management technicians, etc.

Figure 5: PC researchers as a proportion of total researchers


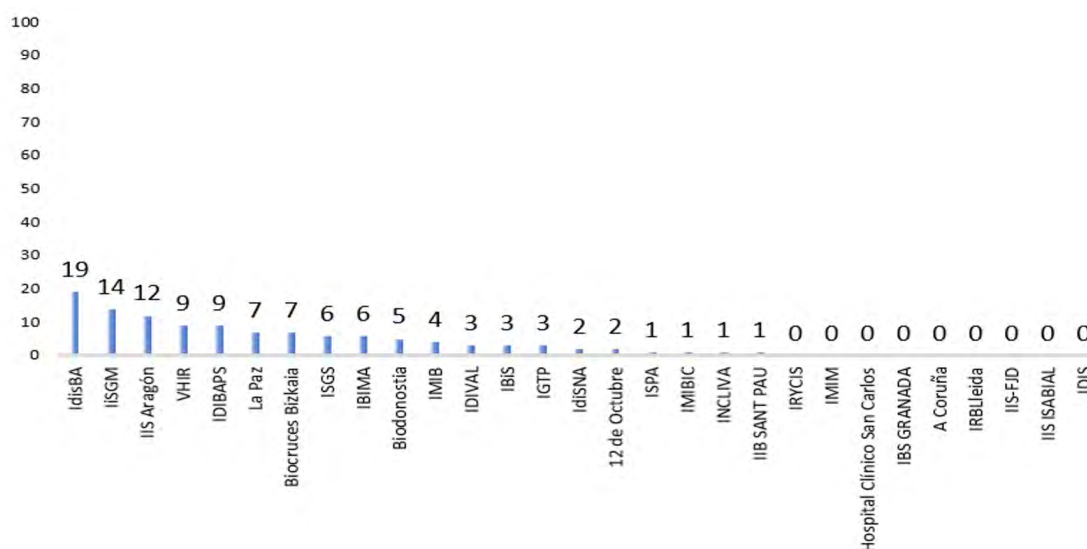
Aspects related to projects or the presence of PC on platforms were also assessed. The results are described below.

Table 4: Support structures and participation in platforms

N=29	Yes	No
Research support unit in PC centres	31.0%	69.0%
Affiliated to SCReN platform	86.2%	13.8%
PC researchers participating in SCReN	34.5%	65.5%

The support units described include the Physical Activity Laboratory, methodological support units, project management and biostatistical support, knowledge management, and health outcomes assessment and analysis, among others.

The involvement of PC in other IIS platforms, such as Data Extraction, Dynamisation and Innovation of the NHS and its effective transfer to the productive sector (ITEMAS), Nutrition and Food, Support for Innovation, Biobank, EATRIS, has been objectified.

Figure 6: Active, competitive national and international public projects with PC IP.


Good practices { XE "5.Good practices" }

The IIS described several practices carried out within their organisation, which are detailed below (in descending order of frequency reported in the questionnaire):

1. Promotion of synergies between PC research and different health and academic fields – 5 IIS
2. Specific intramural calls for PC projects – 4IIS
3. Joint IIS research days with PC participation – 4 IIS
4. PC researchers as lecturers in research courses – 4 IIS
5. Provision of methodological training for PC professionals – 4 IIS
6. Provision of methodological and writing support for PC competitive projects – 4 IIS
7. Participation in stable research structures – 3 IIS
8. Talent retention programmes – 2 IIS
9. Specific calls for intensification in PC – 2 IIS
10. Increased participation in independent clinical trials – 1 IIS
11. RWD projects through data mining platforms – 1 IIS
12. Seeking support from PC management to identify investigators to participate in research projects/ professional network to participate in research projects – 1 IIS
13. Open access publication grants – 1 IIS
14. Research grants for end of residency – 1 IIS
15. Creation of working groups with PC researchers to identify areas of interest and centralise research activities – 1 IIS

SWOT Analysis{ XE "6. Análisis DAFO" }

One of the objectives of this report was to carry out a SWOT analysis (Strengths, Weaknesses, Opportunities and Threats) in order to define strategic lines and actions for the effective integration of these profiles in the research areas of each IIS. The results are presented below. Weaknesses Threats

WEAKNESSES

1. Low presence of PC representatives in IIS governing bodies
2. Only 1/3 of IIS have PC leadership of a scientific area/programme.
3. Less than half have PC researchers on committees such as Innovation, Responsible Research or Training.
4. Only 1/3 of IIS have PC research support units.
5. Low participation of PC in platforms such as SCReN, data extraction, dynamisation, innovation, etc.
6. Low participation of PC researchers in European projects.
7. Lack of common research agendas in PA, training in advanced methodologies, and master's degrees oriented towards translational research.

THREATS

1. The presence of PC researchers on the External Scientific Committees is exceptional.
2. The percentage of groups led by PC researchers is very low.
3. Only one IIS reaches the optimum of 10% of PC researchers of the total.
4. Less than a fifth of IIS have associated clinical groups of PC.
5. HR funding for PC is exceptional (less than one third of IIS).
6. Lack of time for research due to current high pressure of care in PC.
7. Calls for proposals that do not take into account the specific circumstances of PC, and only some Autonomous Communities have specific funding for projects led by PC.

STRENGTHS

1. PC researchers work in a variety of different thematic groups, as the field of PC research is very broad.
2. Most IIS are members of the SCReN platform, which can be very useful for the development of independent studies in PC.
3. Extensive participation in research structures such as RICORS, INVESTEN.
4. IIS PC are well positioned to drive the IMPaCT cohort.
5. Many of the IIS have specific intramural calls for projects or for publication in open access journals.
6. The new priorities of implementation research, social and gender focus, and responsible research are embedded in the research culture of the PC.

OPPORTUNITIES

1. In more than half of the IIS, the PC appears as a constituent entity or there are ascription agreements for the PC structures in several IIS.
2. Most IIS have PC researchers as members of the internal scientific committee.
3. In half of the IIS, the percentage of groups with PC collaborators exceeds 10%.
4. The majority of IIS have an associated clinical group.
5. The average number of projects with PC IP is 4.0.
6. Diversity of research lines led by PC.
7. PC generates essential clinical databases for RWD research.
8. Telematic solutions for meetings and group work reduce the disadvantages of the dispersion of PC.

Strategic lines and actions for effective integration into the research areas of each IIS { XE "7. Strategic lines and actions for effective integration into the research areas of each IIS" }

Strategic lines	Actions
<p>1. Reinforcement of the role of the PC in the governance structures of the IIS, promoting the presence of its members in the IIS.</p>	<ol style="list-style-type: none"> 1. To seek to ensure that the PC in the IIS area of influence is part of the constituent units of the IIS or that cooperation agreements are established with the PC. 2. To generalise the appointment of at least one PC representative to the IIS committee/board. 3. To appoint at least one PC researcher to the ISC. 4. To identify and appoint, if able to play a relevant role, at least one PC researcher to the ESC. 5. To improve the participation of PC researchers or research technicians in the specific committees of the IIS and the more transversal platforms, in particular Data Extraction, Dynamization and Innovation of Industrial Capacities of the NHS, ITEMAS, Biobank, EATRIS, etc.
<p>2. Encouragement of the participation of PC researchers in the IIS</p>	<ol style="list-style-type: none"> 1. To identify PC researchers in the areas and their “natural” fit in already established groups. 2. To identify PC researchers with joint research experience, where candidates for IP can also be identified, to form the group as their own. 3. To assess whether large PC groups can be a source of new groups when strong leaders from different lines of research come together. 4. To extend the creation of associated clinical PC groups as a source of research funding, integrating the different professional categories that make up PC: family doctors, paediatricians, family nurses, midwives, mental health professionals, psychologists, pharmacists, dentists, social workers, etc. <p>The scientific management of the IIS, together with each IIS area manager, in agreement with the research groups of the area and with the support of the PC departments/teaching/research units, will identify PC researchers with whom they share projects, publications or other results, in order to integrate them into the groups of the area or, if they meet the requirements of the groups, to invite them to form such groups.</p>

Strategic lines	Actions
3.Promotion of research in PC	Actions 1. To promote training in research methods and project design 2. Intensification for PC. 3. External stays. 4. Specific intramural calls for PC. 5. To promote the recruitment of human resources for PC. 6. To strengthen and integrate the research units of PC itself into the IIS and identify them as part of the IIS. 7. To promote the establishment of research goals and incentives for research in PC.
4.Promotion of the dissemination of the IIS among PC professionals.	1. To organise PC research conferences and participate in IIS conferences. 2. IIS presentation sessions for primary care teams, teaching units, management teams, etc. 3. Training sessions for research in PC. 4. Collaboration with PC scientific societies.
5.Promotion of PC research in society	1. To publicise PC research. 2. To incorporate social recommendations based on the results obtained. 3. Relationship with patients and patient associations. 4. To promote RRI. 5. Participation in Researchers' Night, Open Science Days. 6. Presence in social networks of researchers and PC projects. 7. To show that research is not always done in test tubes: visualise clinical research, especially on the PC.

Conclusions and Suggestions

Only one third of the accredited IIS have some presence of PC in terms of number of researchers or groups, in the rest the role of PC is moderate or almost non-existent. This means that they do not play a relevant role in the governance or scientific management bodies of the IIS. The IIS with more PC involvement are those that generally report good practices involving PC.

The SWOT analysis suggests some opportunities arising from being the one who generates essential population-based clinical databases for research in large health databases, and that telematic solutions for meetings and group work reduce the disadvantages of PC dispersion.

The recommendations are included in the section on lines of improvement (5 lines) and actions (up to 30 actions) to implement them. The lines are: i) Strengthening the role of PC in the governance structures of the ISS, with 5 actions. ii) Promoting the participation of PC researchers in the IIS, with 7 proposed actions. iii) Promoting research at primary level, with 7 actions. iv) Disseminating the IIS among PC professionals, with 4 proposed actions. v) Promoting the social dissemination of PC research, with 7 actions.

In conclusion, with regard to the role of PC in IIS, only one third of IIS have a significant presence of PC, another third has little, and in the rest is anecdotal or non-existent. There is therefore much room for improvement; it is a challenge that the IIS must meet and that the Partnership and the ISCIII itself cannot avoid. The report can serve as a basis for knowledge of the reality, suggestions for good practice and a significant volume of actions to be developed to reverse this unfavourable situation.

Integration of Nursing Care Research into Health Research Institutes

GT5. *Institute Partnership. Nursing care. 2022.*

Coordination: ISABIAL

Manager: Dr. María Isabel Orts Cortés.

Executive summary

Introduction Nursing care research is essential to improving the quality and safety of care. This report has been produced by the GT5 Nursing Care, which aims to make nursing visible as a scientific profession and to promote nursing research in accredited IIS.

Theoretical Framework The importance of care research is established as a mechanism to consolidate this discipline within the IIS, overcoming barriers in terms of funding, training and institutional recognition.

Methodology The document was developed in four phases, from the identification of IIS with care research groups (GIC) to the collection of data and preparation of the final report. The REDCap platform was used to collect information from the participating groups.

Development and results. The situation of eight GIC from different IIS in Spain was analysed, highlighting the variability in terms of size, resources and lines of research. Of the 34 accredited IIS in Spain, 29 have GIC and a total of 37 groups were identified. There is a high variability in the level of consolidation of the GIC, with 42.1% being emerging, 26.3% consolidated and 31.6% associated clinical groups. The composition of the groups is diverse, with an average of 23 researchers per group, predominantly nursing professionals. Care research faces challenges of consolidation and recognition, with few consolidated groups and an uneven support infrastructure in the different institutes.

Specific actions and future strategies.

- Advice: Improved access to comprehensive research support, including project management and training.
- Funding: Development of specific calls for proposals and diversification of funding sources.
- Training: Need to broaden the range of training in research, linking theory with clinical practice.
- Dissemination and visibility: Creation of national networks for collaboration and knowledge exchange.

Conclusions. Large disparities are identified between the IIS CIG in terms of their consolidation and institutional support. It is recommended to increase the visibility of care research, to strengthen specific training and to facilitate the participation of nursing professionals in scientific decision-making bodies. This report provides a starting point and a roadmap for the promotion of nursing research in the IIS of the Spanish National Health System.

Introduction

The inclusion of nursing care research in the IIS is essential to improve the quality and safety of care and to make nursing visible as a scientific profession. This report is the result of the “Health Research Institutes Partnership” initiative, coordinated by the Institute of Health Carlos III, which aims to promote care research

in all accredited IIS. Group GT5 NURSING CARE (GT5-C.ENF) to Incorporate Nursing Care Research. Therefore, the objectives were to identify good practices, to determine the current status of nursing care research groups (hereafter GIC) and to define strategic lines and actions aimed at the effective integration of CIG in the research areas of each IIS.

Theoretical Framework

Nursing care research is essential for the development of the health care system and the quality of care. Care research groups are emerging as an essential mechanism for consolidating this type of research in the IIS. GICs are challenged to balance their opportunities with other more established areas of research and require continued support in terms of funding, training and institutional recognition.

Methodology

The preparation of this document was divided into four phases:

First phase

The working group, led by the coordinator, proceeded to identify the accredited IIS in Spain that had a care research group (GIC) and its principal investigator.

At the same time, a consensus was reached on what information needed to be collected from these groups in terms of their composition and scientific output.

Concurrently, a review of articles published on the status of different CIG in some of the accredited IIS was carried out. Their conditions, the characteristics of their researchers and the support mechanisms they receive are described.

Second phase

Firstly, contacts with the heads of the research groups of the accredited IIS were obtained from previous databases, a review of the IIS websites or through direct consultation (by e-mail or telephone) with the scientific and administrative heads of the IIS for which no information was available.

In this phase of the study, the necessary information was collected through the REDCap platform (1,2), hosted by the Institute of Health Carlos III, as part of a study carried out by Investén-ISCIII on care research groups in the stable research structures of the ISCIII. The data collection period was from July 2022 to 10 November 2022. Periodic global and individual reminders were made to ensure maximum representation of all those involved. The working group coordinator was responsible for the synthesis of it. Where verification was required, the GIC managers were contacted directly by e-mail or telephone.

Third phase

The first draft of the document was prepared by the different members of the working group and the relevant aspects were agreed.

Fourth phase

Finally, the final document was agreed upon by all members of the working group and the present document was produced.

Therefore, this document is the result of the opinion of research experts in our country, of the leaders of the IIS CIGs and of nurses belonging to other IIS groups, and it proposes a starting point and a roadmap to promote and support nursing research in the context of the IIS of the Spanish National Health System.

Development and Results

1. Comparative analysis of the situation of eight care research groups affiliated to different accredited health research institutes in Spain.

The conditions of the care research groups differ depending on the accredited reference institute to which they are attached. The situation of eight groups is presented below as an analysis of the current situation, taking into account the evaluation criteria of the research groups based on the review of articles published on the subject.

Multidisciplinary Nursing Research Group, Vall d'Hebron Research Institute. (3)

In 1994, the Vall d'Hebron Hospital had a position dedicated exclusively to supporting care research.

- In 2014, the Healthcare Research Group was born (2010), classified as an Emerging Group, and in 2019 it was renamed as the “Nursing Multidisciplinary Research Group”.
- Requirements to become a researcher: Solid research training, active participation in projects and stable work relationship.
- Structure and functioning: Regular meetings for project follow-up and strategic decision-making.
- Main researchers: Professionals with extensive research experience who give impetus to the group's activities, identify promising lines of research and provide methodological and dissemination support.
- Research promotion: Development of specific programmes to intensify research in nursing and physiotherapy.
- Dissemination of results: Publication of results on the corporate website.

The priority axes are in line with those established in the Strategic Plan for Research and Innovation in Health, defined by the Catalan Department of Health, and in turn with the Horizon 2020 strategy.

Emerging Group IMIBIC-GE08 “Comprehensive Nursing Care – Multidisciplinary Perspective”. Maimonides Biomedical Research Institute of Cordoba (IMIBIC)(4)

It was born as 'Multidisciplinary Research Group in Integrated Care' (2007), attached to the University of Cordoba. It was renamed to “Comprehensive Nursing Care – Multidisciplinary Perspective” in 2019.

- The MR of the group is a member of the IMIBIC Scientific Council.
- Composed of Nursing, Medicine, Social Work, Sociology, Anthropology, Clinical Documentation of Primary Care, Specialised Care, University of Castilla-La Mancha, University of Brazil, several Andalusian Universities, Pensioners, University of Italy. Very intense collaboration with other universities, both national and international.
- It is mainly staffed by Masters and Doctoral students.
- It has the possibility of using university and hospital facilities.

Clinical Nursing and Community Health Group of the Biobizkaia Health Research Institute (5)

It was created in 2020 and has reached the status of an excellent consolidated group.

- Its working areas are: General care research; Evidence-based practice and implementation of good practice in clinical care; Special care of critically ill patients; Community health, health promotion and health promotion activities; Health education; Social epidemiology and healthy environments; and Chronicity and healthy ageing.
- It is made up of a multidisciplinary team of health professionals from the different health organisations of Osakidetza in Bizkaia and teaching and research staff from the University of the Basque Country.

Advanced Nursing Care Research Group (ENFERAVANZA) of the Biomedical Research Institute of Murcia, IMIB-Arrixaca (6)

It was created under the name “Quality Management and Patient Safety. Occupational Health. Gender and health. Nursing care in population groups” (2015), coordinated by a professor of the Faculty of Nursing.

- IMIB-Arrixaca's commitment to supporting research in nursing and primary care led to a positive assessment in the ISCIII reaccreditation, which was achieved in 2019.
- Renamed as the “Advanced Nursing Care Group” in 2018, it has its own website.
- Composed of professors, staff and clinical professionals, but also teaching and research staff.
- Several members of the group actively participate in IMIB-Arrixaca's advisory bodies: internal scientific committee, quality commission, organising committees for events.
- Partnerships and collaborations with other institutions: Research Unit on Care and Health Services of the Institute of Health Carlos III (Investén-ISCIII), Regional Coalition for Active and Healthy Ageing, framework agreements with various universities.
- Partnerships and collaborations with other intra-institute groups and other institutes.

Group for Research in Nursing Care. Gregorio Marañón Health Research Institute (IiSGM) (7)

Group for Research in Nursing Care (2012). Created as an emerging group. Currently classified as an “Associated Group”.

- Multidisciplinary: areas of knowledge in nursing, physiotherapy, anthropology and sociology. The group integrates professionals from the care and university sectors, as well as from the primary care and hospital sectors.
- It promotes research intensification programmes and intramural aid.
- It has access to university and hospital services and facilities: bibliographic funds, data managers, documentation managers, statistical software, online platform for the design, development and management of electronic notebooks for data collection in research studies and multicentre projects, and research support services.
- Nursing Research Support Unit: advisory role, promoter and informer of everything related to nursing research.
- Own office resources (self-funded by the group's projects).

- The group also has access to the entire training plan and research seminars offered by the IiSGM.

Healthcare Research group Health Research Institute of San Carlos Hospital (IdISSC) (8)

- The group was formed by the initial impulse of the Hospital's Nursing Management in 2011 and is directed by the Research Area Supervisor.
- Main researchers of the research group: there are two, one from the management care field and the other from the university field. The group is made up of professionals from the healthcare and university spheres, mainly nurses.
- Membership of the group of specially recruited singular units: stomatherapy, pressure ulcers, intravenous therapy, for example.
- Integration into the team of members of the Directorate of Nursing and the Dean's Office of the Faculty of Nursing.
- As part of the IdISSC, the GIC has access to all the research support units of the IdISSC, such as: Flow Cytometry Unit, Genomics Unit, the Biobank, Methodological and Analytical Support Units, or support and guidance teams aimed at creation and development, as in the case of the Innovation Unit.

Research Group in Nursing and Health Care Puerta de Hierro-Segovia de Arana Health Research Institute (IDIPHISA) (9)

Research Group in Nursing and Health Care (2013).

- Involvement of the nursing management of the hospital in which the institute is integrated.
- Synergies in the group between university teaching staff and clinical care centres.
- This group is part of one of the five areas of the Institute, namely surgical research, transplants and technologies.
- If the researcher has not contributed to scientific production in the last two years, he/she will be removed from the group.
- There is a need for intensification grants for long-term projects to give them continuity.
- The group relies on the resources of the hospital itself, the university, the centres where the members of the group work and all those offered by IDIPHISA itself: Care Research Support Unit, Biostatistics Unit, Library Unit, Innovation Unit and other shared platforms (IT Unit, Training Unit, Reprographics Unit, plotter, classrooms and meeting rooms, audiovisual material, etc.).
- In terms of staff recruitment, a milestone was the award of a research assistant through the Community of Madrid's Youth Employment Plan for the period March 2018-March 2020.

Valdecilla Health Research Institute (IDIVAL) (10)

In February 2017, the Nursing Research Group was accredited as an emerging group following an external audit process.

- In 2017, of the five groups that applied to be created, three were accredited, including the Nursing Research Group, which was recognised as an emerging group and continues to be an emerging group.
- The first group to be accredited in 2017 was made up of nine nurses, five of whom were full-time lecturers in the Department of Nursing at the University of Cantabria and three were associate lecturers.

Seven of the nine members of the group had a doctorate. Currently there are 20 members, most of them professors (11 professors, 4 with a clinical profile, 5 clinicians and teachers).

IDIVAL support actions for emerging groups and nurses

- Call for Next-Val (Next Generation Valdecilla) grants aimed at young researchers (main researchers under 45 years of age who have never had access to funding as such through a national or international competitive call or this call). Maximum grant of €25,000 (total amount of the call €125,000). It is preferred that the MR and the group belong to the field of nursing and primary care.
- Promotion of the figure of the new researcher in the groups through recognition in the production grants.
- Priority for nursing and primary care professionals in research methodology training activities.
- In the Institute's calls for proposals, positive priority is given to MRs working in nursing or primary care.
- The Intensification Programme is open to nurses.
- Inclusion of nurses in the synergy strategy of research groups, with financial support for invitations to national and international benchmark researchers.
- National call for research projects “Nursing Valdecilla” with a category for the best national project and another to be developed by a nurse MR from Valdecilla.
- “Inn-Val” programme: funding of innovation projects led by researchers from the IDIVAL environment. One of the priority lines is the development of innovation in primary care and nursing.

2. Evaluation criteria for research groups in some health research institutes

The research groups in the institutes are usually classified into three categories, with different names depending on the institute, but which are obligatory and are evaluated from time to time, usually every four or five years. If the required minimums are not reached, the excluded groups change their name in order to continue in the IIS, and thus their access to grants, funding and visibility. The permanence of groups and researchers in the institutes depends on this.

Some of these classifications are explained below, with the necessary merits gathered from the available information.

Vall d'Hebron Research Institute (VHIR) for Emerging Group (3):

- They must have carried out jointly funded research projects in the last five years.
- During this period, they must have a series of joint publications of proven quality and sufficient number and/or the development of patents or joint health activities.
- The group must be made up of at least two researchers, one of whom must be a doctor affiliated to the VHIR (by law or by contract for more than two years).
- Have at least one active research project funded by a competitive public call; one of the members of the group must be the main researcher of the project.

Maimonides Biomedical Research Institute of Cordoba (IMIBIC) for Emerging Group

At least 70% of the merits indicated in Figure 1 must be met.

Cuadro 1. Criterios para la valoración de Grupo Emergente en función de los méritos científicos	
Criterios para la valoración de méritos	Criterios puntuación
Publicaciones	4
- Factor de impacto acumulado en los últimos cinco años ≥ 30 (trabajos de autoría propia)	1
- Número de publicaciones originales en ISI ≥ 10	1
- De esas publicaciones en los cuartiles Q1 y Q2 ≥ 4	1
- Índice H del IR ≥ 4 (2009 al 2013)-WOS	1
Proyectos competitivos concedidos y desarrollados	2
- Plan Nacional I+D+i, Programa Marco, Internacionales En los últimos cinco años ≥ 1	1
- De la Junta de Andalucía En los últimos cinco años ≥ 1	1
Financiación	1
Financiación obtenida en los últimos cinco años $\geq 30.000,00$ euros	1
Participación en redes nacionales (RETIC, CIBER) o internacionales	1
Internacionalización del grupo	1
Publicaciones colaborativas con grupos extranjeros ≥ 1	1
Patentes-Spin-off	1
Número de patentes aprobadas ≥ 1	1
Ensayos clínicos	2
Fase I-II,	
- Publicados en revista en otros cuartiles ≥ 1	1
- Que no haya sido publicado en ninguna revista ≥ 1	1
Contratos suscritos con empresas	1
Financiación obtenida en los últimos cinco años ≥ 50.000 euros	1
Formación Recursos Humanos	1
Tesis Doctorales dirigidas en los últimos cinco años ≥ 1	1
Total puntuación méritos	14

Figure 1. Requirements for classification as an IMIBIC Emerging Group (4)

Biomedical Research Institute of Murcia, IMIB-Arrixaca for Emerging Group

- At least one project funded by regional, national or international calls in the last three years, with a record of co-authored publications (less than 20), with a cumulative impact index of less than 40; doctoral theses; patents and trademarks; mixed team composition between academics-basic and clinicians (6).

Gregorio Marañón Health Research Institute (IiSGM) for Associated Group (7)

- Groups that develop or collaborate in clinical trials and/or have an impact factor of less than 30 points in 5 years, without National Plan projects, with sporadic funded projects.

Health Research Institute of San Carlos Hospital (IdISSC) for emerging and consolidated groups.

- Emerging group: one of the criteria is an impact factor of 15, according to the Journal Citation Reports (JCR) index, accumulated over the last five years.
- Consolidated group (Figure 2)

Cuadro 1. Requisitos para ser considerado Grupo Consolidado en el Instituto de Investigación Sanitaria San Carlos (IdISSC)
1. Trayectoria común de los integrantes del grupo en los últimos cinco años
2. Dos proyectos o más con financiación competitiva
3. Factor de Impacto JCR igual o mayor a 40
4. Publicaciones en primer y/o segundo cuartil igual o superior al 30% de las publicaciones del grupo
5. O bien, si no se cumplen todos los criterios anteriores, presentar un factor de impacto JCR igual o superior a 100

Figure 2. Requirements to be considered as a consolidated group in the IdISSC (8)

Puerta de Hierro-Segovia de Arana Health Research Institute (IDIPHISA) for all types of groups.

The research groups at the IIS Puerta de Hierro are classified as consolidated, emerging or clinical/associated. Requirements for classification and permanence in one or the other (Figure 3).

Cuadro 1. Criterios para la valoración de Grupo Emergente en función de los méritos científicos	
Criterios para la valoración de méritos	Criterios puntuación
Publicaciones	4
- Factor de impacto acumulado en los últimos cinco años ≥ 30 (trabajos de autoría propia)	1
- Número de publicaciones originales en ISI ≥ 10	1
- De esas publicaciones en los cuartiles Q1 y Q2 ≥ 4	1
- Índice H del IR ≥ 4 (2009 al 2013)-WOS	1
Proyectos competitivos concedidos y desarrollados	2
- Plan Nacional I+D+i, Programa Marco, Internacionales	1
- En los últimos cinco años ≥ 1	
- De la Junta de Andalucía	1
- En los últimos cinco años ≥ 1	
Financiación	1
Financiación obtenida en los últimos cinco años $\geq 30.000,00$ euros	1
Participación en redes nacionales (RETIC, CIBER) o internacionales	1
Internacionalización del grupo	1
Publicaciones colaborativas con grupos extranjeros ≥ 1	1
Patentes-Spin-off	1
Número de patentes aprobadas ≥ 1	1
Ensayos clínicos	2
Fase I-II,	
- Publicados en revista en otros cuartiles ≥ 1	1
- Que no haya sido publicado en ninguna revista ≥ 1	1
Contratos suscritos con empresas	1
Financiación obtenida en los últimos cinco años ≥ 50.000 euros	1
Formación Recursos Humanos	1
Tesis Doctorales dirigidas en los últimos cinco años ≥ 1	1
Total puntuación méritos	14

Figure 3. Merits to be classified in an IDIPHISA research group (9)

Valdecilla Health Research Institute (IDIVAL)

There is no scale as such. The following aspects are taken into account:

- Consolidated, emerging, associated or transversal group.
- Consolidated group: groups with a stable research projection, with publications and stable external competitive funding in the last five years, and with technical or research staff dedicated exclusively to research.
- Emerging Group: less than three years old. After these three years, it must be re-evaluated by the IIS Scientific Committee and classified as Associate or Consolidated. In exceptional cases it may be extended for a further two years.
- Associate Group: more than three years old, but not considered by the external scientific committee to have reached the minimum to be a consolidated group.
- Transversal group: they exist without the need for classification or to be framed within a specific field of research. It is a fundamental level of research.
- Recently created groups: they have been in existence for more than three years, so they cannot be considered as emerging and do not meet the requirements for a consolidated group – They will be re-evaluated after three years.

3. Characteristics of Care Research Groups in Health Research Institutes

Regarding the presence of care research groups in health research institutes, of the 34 accredited IIS in Spain, 29 have GICs, of which four do not (IIS BIODONOSTIA, in Donostia; IISFJD and IRYCYS, in Madrid; and IISGS, in Galicia) and one, IIS-PRINCESA, in Madrid, has a CIG in the process of being incorporated.

Information was collected from all (100% participation) of the IIS with specific care research groups. Most of them have only one GIC (there are five groups at IIS Aragón, three groups at IBIMA, Malaga, two at IBIS, Seville and IdisNA, Navarra), with a total of 37 GIC (Table 1). In addition, this document has also collected information on the strategies (present and future) of nurses from non-specific care research groups in most of the IIS without GICs.

The area of the IIS where the GIC is integrated is quite variable. In 15 of the IIS the word care or nursing does not appear in the area where the groups are integrated: IBIMA, IBIS, ibs.GRANADA, IBSAL, IDIBELL, IDIPAZ, IDIPHIM, IdisBa, IdISSC, IGTP, IIS BIOCUCES, ISS LA FE, IMB, IMIBIC, IR-HUVH; 2 of them are in transversal areas: I+12, IDIVAL; and 3 others have no assigned area: IIB SANT PAU, INCLIVA and IIS-PRINCESA (to be included); 5 are in areas where the word care appears together with other non-specific terms: IdisNA, INIBIC, IRBLLEIDA, ISABIAL, ISPA; and three are specific to care or nursing: IDIBAPS, IsSGM, highlighting the IIS Aragón, which has five groups in the field of "Research and Innovation in Nursing and Health Care". (Table 2).

Table 1. Accredited Health Research Institutes and care research groups

IIS	Name of the care research group
I+12 (RESEARCH INSTITUTE HOSPITAL 12 DE OCTUBRE)	InveCuid
IBIMA– BIONAND PLATFORM (BIOMEDICAL RESEARCH INSTITUTE OF MALAGA AND PLATFORM IN NANOMEDICINE)	(1) Quality and safety in care, laboratories and haematology (2) C-13 Chronicity, Dependency, Care and Health services (3) INVESCUIDA
IBIS (INSTITUTE OF BIOMEDICINE OF SEVILLE)	(1) Complex Care, Chronicity and Health Outcomes (2) CTS 969– Innovation in Care and Social Determinants in Health
IBS.GRANADA (BIOSANITARY RESEARCH INSTITUTE OF GRANADA)	Ee12-HYGIA: Care and determinant factors of health (Emerging)
IBSAL (INSTITUTE FOR BIOMEDICAL RESEARCH OF SALAMANCA)	Nursing research in cardiology
IDIBAPS (AUGUST PI I SUNYER BIOMEDICAL RESEARCH INSTITUTE)	Care research

IIS	Name of the care research group
IDIBELL (BELLVITGE BIOMEDICAL RESEARCH INSTITUTE)	Nursing research (GRIN)
IDIPAZ (HOSPITAL LA PAZ INSTITUTE FOR HEALTH RESEARCH)	Health care research
IDIPHIM (IIS PUERTA DE HIERRO HEALTH RESEARCH INSTITUTE)	Nursing and Health Care Research
IDIS (HEALTH RESEARCH INSTITUTE OF SANTIAGO DE COMPOSTELA)	Nursing, management and care
IDISBA (HEALTH RESEARCH INSTITUTE OF THE BALEARIC ISLANDS)	Care, Chronicity and Evidence in Health (CuRES)
IDISNA (HEALTH RESEARCH INSTITUTE OF NAVARRA)	(1) Research on new Nursing practices INNO-CARE (2) Research in Nursing Care
IDISSC (HEALTH RESEARCH INSTITUTE OF THE HOSPITAL CLÍNICO SAN CARLOS)	Care research
IDIVAL (VALDECILLA HEALTH RESEARCH INSTITUTE)	Nursing research
IGTP (GERMANS TRIAS I PUJOL RESEARCH INSTITUTE)	GRINCARE
IIB SANT PAU (SANT PAU RESEARCH INSTITUTE)	Research in nursing care
IIS ARAGÓN (HEALTH RESEARCH INSTITUTE OF ARAGÓN)	(1) Safety and care (2) Care Research. Sector III Zaragoza (3) Nursing Research Group in End of Life Processes (4) Primary Care Nursing Research Group of Aragon (5) Relational Leadership in Health Care

Table 1. Accredited Health Research Institutes and care research groups

IIS	Name of the care research group
IIS BIOCUCES (BIOBIZKAIA HEALTH RESEARCH INSTITUTE)	Clinical Nursing and Community Health
IIS BIODONOSTIA (BIODONOSTIA HEALTH RESEARCH INSTITUTE)	No care research group

IIS	Name of the care research group
IIS LA FE (HEALTH RESEARCH INSTITUTE HOSPITAL LA FE)	Art and Science in Healthcare
IISFJD (FUNDACIÓN JIMÉNEZ DÍAZ HEALTH RESEARCH INSTITUTE)	No care research group
IISGM (GREGORIO MARAÑÓN HEALTH RESEARCH INSTITUTE)	Nursing Group
IISGS (GALICIA SUR HEALTH RESEARCH INSTITUTE)	No care research group
IIS-PRINCESA (HOSPITAL LA PRINCESA HEALTH RESEARCH INSTITUTE)	Nursing Care in Health (Group in process of incorporation)
IMIB (BIOMEDICAL RESEARCH INSTITUTE OF MURCIA VIRGEN DE LA ARRIXACA)	Advanced nursing care
IMIBIC MAIMONIDES BIOMEDICAL RESEARCH INSTITUTE OF CORDOBA	Comprehensive nursing care. Multidisciplinary perspective
IMIM (HOSPITAL DEL MAR RESEARCH INSTITUTE)	Research in nursing care
INCLIVA (HOSPITAL CLÍNICO DE VALENCIA-INCLIVA FOUNDATION HEALTH RESEARCH INSTITUTE)	Associated Healthcare group
INIBIC (BIOMEDICAL RESEARCH INSTITUTE OF A CORUÑA)	Nursing and Health Research Group: Methodology and Applications
IRB LLEIDA (BIOMEDICAL RESEARCH INSTITUTE OF LLEIDA)	Research group of health care (GReCS)
IRYCIS (RAMÓN Y CAJAL HEALTH RESEARCH INSTITUTE)	No care research group
IR-HUVH (HOSPITAL VALL D'HEBRON RESEARCH INSTITUTE)	Multidisciplinary Nursing Research
ISABIAL (BIOMEDICAL AND HEALTH RESEARCH INSTITUTE OF ALICANTE)	Innovation in Nursing Care
ISPA (HEALTH RESEARCH INSTITUTE OF ASTURIAS)	Care research

Table 2. Area of the IIS in which the Care Research Group is integrated

IIS	Area
i+12	Transversal
IBIMA	Oncology and haematology
IBIMA	Neurosciences, Chronicity, Aging and Health in Vulnerable Populations Cardiovascular diseases
IBIS	Cardiovascular, Respiratory and Other Pathology (2 GIC)
ibs.GRANADA	Epidemiology and Public Health
IBSAL	Cardiovascular
IDIBAPS	Care
IDIBELL	Translational Medicine
IDIPAZ	Large Systems Pathology
IDIPHIM	Surgical Research, Transplantation and Healthcare Technologies
IDIS	Platforms and Methodology Area
IdisBa	Public Health, Epidemiology, Clinical and Health Services
IdisNA	Primary Care, Healthcare and Health Services
IdISSC	Other Large Systems
IDIVAL	Transversal
IGTP	Community health
IIB SANT PAU	Not assigned to area (Associated group)
IIS Aragón	Research and innovation in nursing and healthcare (5 GIC)
IIS BIOCRUCES	Primary Health Care, Prevention and Chronic Diseases
IIS LA FE	Infection, inflammation and chronicity
IiSGM	Nursing Group
IIS-PRINCESA	Not assigned to area
IMIB	Epidemiology, Public Health and Health Services
IMIBIC	Active ageing and fragility
IMIM	Health care
INCLIVA	Not assigned to area (Associated group)
INIBIC	Population Health, Health Care

IIS	Area
IRBLLLEIDA	Chronic Diseases, Surgery and Health Cures
IR-HUVH	Chronic, Prevalent and Age-related Diseases; Women's and Children's Health and Minority Diseases
ISABIAL	Translational Research in Medicine, Chronicity and Health Care
ISPA	Primary Care and Health Services Research

Of the 38 CIGs, 42.1% are emerging research groups, 26.3% are consolidated (or pre-consolidated) research groups and 31.6% are associated clinical groups (this group includes those in the process of integration) (Figure 3).

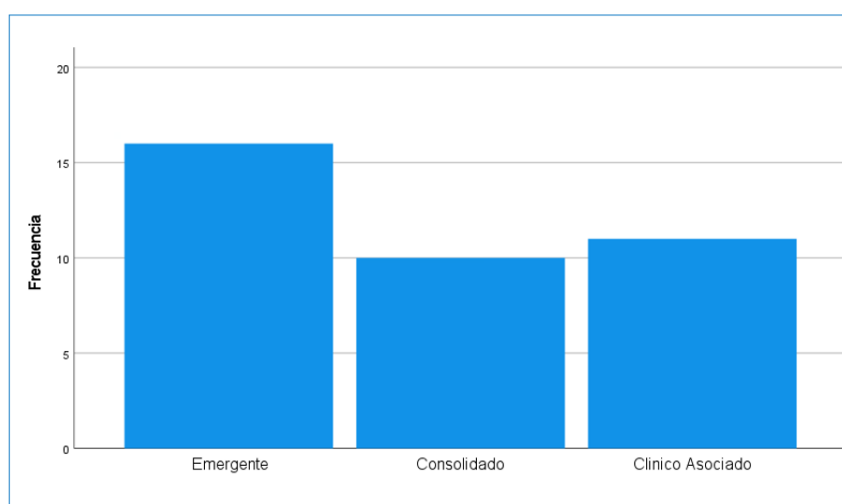


Figure 3. Level of groups

With regard to the assessment of the group, 27% do not meet the criteria, an aspect that reflects the conditions in which nurse researchers find themselves with regard to the criteria for group accreditation (Table 3).

Table 3. Group assessment

	n	%
Excellent	11	29.7
Standard	16	43.2
Does not comply	10	27.0
Total	37	100.0

The composition of the groups is numerous, with an average of 23 researchers. There are GIC where all the members are care professionals and in some cases there are no professionals linked to the academic field (Table 4). In the case of the 102 members, there is one GIC that has 12 research groups in the field of care.

Table 4. Members making up the group (n=38)

	Minimum	Maximum	Mean	of
Total	5	102	23.13	18.08
Nursing staff	5	80	20.21	14.84
Other professional categories	0	22	2.92	5.22
University	0	25	7.87	7.36

In terms of the other professions that make up the groups, we see that they come mainly from medicine and physiotherapy, followed by psychology, nutrition and dietetics or statistics (Table 5).

Table 5. Members of other degrees

	*Answers		% Cases	
	N	%		
Other professionals	Medicine	10	20.4	45.5
	Biology	2	4.1	9.1
	Pharmacy	1	2.0	4.5
	Statistics	4	8.2	18.2
	Physiotherapy	10	20.4	45.5
	Podiatry	2	4.1	9.1
	Psychology	7	14.3	31.8
	Nutrition and dietetics	4	8.2	18.2
	Other	9	18.4	40.9
Total	49	100.0	222.7	

*%> 100 %, multiple choice question

The vast majority of GICs have no pre- or post-doctoral fellowships, and those GICs that have received them have mostly received only one; the data are similar for intensification contracts (Table 6).

Table 6. Fellowship and intensification

	n	%	
Pre-doctoral fellowships	0	23	60.5
	1	9	24.3
	3	2	5.4
	4	4	10.8

	n	%	
Post-doctoral fellowships	0	30	78.9
	1	5	13.2
	2	1	2.6
	3	2	5.3
Fellowship of intensification	0	26	68.4
	1	6	15.8
	2	5	13.2
	3	1	2.6

In more than half of the internal committees of the IIS, 57.9%, there are no nursing professionals, while in the external committee the percentage of non-representation rises to almost 90% (Table 7).

Table 7. Nursing professionals in Committees

	n	%	
Internal committee	No	22	57.9
	Yes	16	42.1
External committee	No	34	89.5
	Yes	4	10.5

4. Specific actions and proposed future strategies for the incorporation of care research.

This section presents the strategies considered by the different managers of the GICs and nursing professionals from other groups in the IIS, which could constitute specific and future lines of action in order to homogenise and promote nursing research. The structured questionnaire was used to collect information from the researchers in charge of the GICs in the areas of "Advice", "Funding", "Training" and "Dissemination, diffusion and information".

In general, the GICs show considerable variability between the different institutes in terms of the specific actions collected. While in most cases similar support to other research groups is offered, in some cases this support is non-existent or limited.

Advice

Specific actions

The most common advisory services include:

- Comprehensive research support: CIGs can access advice on project development, search for calls for proposals, methodological design, statistical analysis, grant management, training, scientific writing and dissemination of results.

- Promotion of synergies: Collaboration between care centres (hospitals and primary care) and universities is encouraged to strengthen care research.
- Specialised management: Dedicated staff will be assigned to manage care research projects and facilitate their development.
- Committees and support structures: Nursing research committees and research sub-directorate structures are in place to provide personalised advice to professionals.

Future strategies

Care research groups request specific and targeted support for their needs. This support focuses on:

- Strengthening research capacity: By training in statistics, computing and project management, and in seeking and obtaining competitive funding.
- Streamlining administrative procedures: By providing a dedicated administrative officer and simplifying bureaucratic procedures.
- Improving collaboration: By creating networks of care researchers at national level and organising meetings to share experience and knowledge.
- Developing specialised human resources: By recruiting data managers and expanding the role of project managers.
- Setting clear objectives and follow-up: By appointing expert mentors to help GICs achieve their goals.

Funding

Specific actions

The CIGs have implemented a number of specific actions to secure their funding and enhance their research activities. These actions focus on:

- Intramural calls: Specific calls for nursing staff have been established to promote research and leadership in the field. These calls include fellowships, sabbaticals and grants for competitive projects.
- Support in finding external funding: Accompaniment, advice and methodological support are offered to the GICs to enable them to participate in national and European calls for proposals, with the aim of obtaining external funding and generating income for the institutes.
- Promotion of research in emerging areas: Specific calls for grants have been launched for underdeveloped areas of care research or for emerging groups.
- Recognition and encouragement: Prizes have been created to recognise and reward quality publications and research projects carried out by nurses, thereby encouraging scientific production.
- Prioritisation of human resources: Priority has been given to the allocation of human resources, such as research staff, to emerging groups to strengthen their research capacity.
- Development of internal funding sources: Intramural grants specifically for nursing research have been created to complement external funding sources.
- Dissemination of opportunities: Active work will be undertaken to disseminate calls for proposals, grants and other funding opportunities targeted at GICs.

- Linking research with professional career: Scientific production, participation in research projects and obtaining a doctorate have been included as qualitative requirements for the development of a professional career in nursing.

Future strategies

Future strategies to secure funding for Care Research Groups (GICs) focus on strengthening collaborative networks, improving research visibility, diversifying funding sources and providing more stable support for researchers.

The main strategies proposed are:

- Diversifying funding sources:
 - Stable funding: Establishment of an annual core funding for GICs, which will allow for better planning and implementation of projects.
 - Specific calls for proposals: Creation of targeted calls for projects not funded through other channels, as well as for emerging groups and early career researchers.
 - Publication and dissemination support: Provision of grants for the translation and publication of scientific articles and for participation in national and international conferences.
 - Support services: Funding of external services such as statistical and other specialised consultancies.
 - Researcher mobility: Establishment of fellowship programmes for training in centres of excellence, both nationally and internationally.
- Participation in collaborative projects: Encouragement of the participation of GICs in multi-centre and coordinated projects to gain experience and establish new collaborations.

Training

Specific actions

In most institutes, research training activities aimed at GICs tend to be general in nature, covering a wide range of health professionals, and are not always specifically focused on the specificities of care research.

The most common training activities include:

- Basic training: Introductory courses in research methodology, statistics and literature searching.
- Thematic seminars: Specialised sessions on specific topics such as scientific publication.
- Dissemination of opportunities: Information on courses, events, conferences and calls for proposals of interest to researchers.
- Structured training programmes: Training programmes at three levels (basic, intermediate and expert), including doctors and nurses.
- Training stays: Fellowships for stays in centres of excellence at international level.
- Specific training for residents and other professionals: Courses and workshops adapted to the needs of each group.
- Accredited courses: Offer of accredited courses in research aimed at nursing professionals.

- Grants and leaves of absence: Intensification grants to devote time exclusively to research and sabbaticals for research stays abroad.
- Official Master's degrees: Promotion of official Master's degrees in research.

Future strategies

Future strategies for GIC research training focus on broadening and diversifying training offer, as well as promoting collaboration and the use of new technologies.

The main strategies proposed are:

- Expansion and diversification of training offer:
 - Translational training: Courses that connect research to clinical practice.
 - Diverse methodologies: Training in qualitative, mixed methods and advanced research designs.
 - Specialised tools: Access to specialist data analysis tools.
- Open access to training: Offer of a wider range of specialist training resources free of charge.
- Continuing programming: Establishment of a structured annual education calendar.
- Basic and advanced training: Courses for all levels of expertise.
- Encouragement of collaboration:
 - Meetings and workshops: Organization of events to share knowledge and experience.
 - Care networks: Strengthening of care research networks.
 - Specific seminars: Creation of spaces for discussion of issues relevant to care research.
- Training stays: Building loyalty to the programme of stays in centres of excellence.
- Use of technologies: Training of nurses in the use of technological tools for research.
- Collaborative platform: Development of a web platform to facilitate access to research resources and tools.

Diffusion and Dissemination of Care Research

Specific actions

The Care Research Groups (GIC) undertake a number of specific actions to make their research known to a wider audience, both at a professional level and to society in general. These actions focus on:

- Communication to professionals: Through newsletters, social networks and internal events, nursing professionals are informed about the latest research, calls, congresses and projects. Annual interdepartmental research conferences and participation in regular seminars organised by research institutes. Digital tools are used to facilitate dissemination of information and collaboration between researchers.
- Dissemination to the public: Lectures, conferences and participation in scientific dissemination events are organised to bring care research closer to the general public.
- Publication support: Financial and methodological support is provided to researchers to publish their work in scientific journals.

- Internal and external events: Research conferences are organised, such as the Institute's annual research conference, intra-hospital nursing conferences to disseminate scientific activities, seminars and participation in scientific events such as European Researchers' Night, Pint of Science, Science Week.

Future strategies

The main actions proposed are:

- Establishment of a national network: Development of a collaborative platform connecting nurse researchers at national level, facilitating the exchange of knowledge and experience.
- Financial support: Provision of direct grants to cover the costs of translation, open access publication and participation in conferences, which will increase the visibility of research.
- Promotion of inter-institutional cooperation: Organisation of conferences and meetings to strengthen networks between different institutions and promote multidisciplinary research.
- Participation in multidisciplinary events: Encouragement of nurses to participate in multidisciplinary innovation and research events.
- Invest in talent: Encouragement of intramural funding and pre-doctoral fellowships to increase the quality and impact of research.
- Use of multiple channels: Use of forums, media and digital platforms to disseminate research results.
- Dissemination events: Organisation of interdisciplinary events to promote nursing research to a wider audience.
- Increase visibility of nurse-led projects: Highlighting nursing research projects in different communication channels.
- Open access publication: Directly funding open access publication to ensure maximum dissemination of results.

Other Actions

Specific Actions

- Active participation in decision-making: This involves nurse researchers having a say in strategic decisions about research, ensuring that their needs and perspectives are taken into account.
- Institutional prioritisation of nursing research: By making nursing research an institutional priority, resources are allocated and mechanisms are put in place to support and promote this activity.

Future strategies

- More time for research: With more time, nurse researchers can deepen their projects, increase their productivity and produce more impactful results.
- Specific positions: The creation of specific positions for research nurses ensures exclusive dedication to this activity and facilitates the planning and implementation of long-term projects.

Conclusions and Suggestions

The analysis of 34 accredited IIS shows a high degree of heterogeneity and variability in terms of size, structure, resources and level of consolidation of the Care Research Groups. Nursing care research still does not have the visibility it deserves within the IIS, and nurses are often under-represented in management and decision-making bodies. Similarly, GICs often lack sufficient resources, both financial and human, to optimally develop their research activities. There is a need to provide specialised research training for care professionals, adapted to their needs and to the specificities of research in care. The creation of collaborative research networks at national level is essential to strengthen care research and to share knowledge and experience.

It has been observed that some of the 34 accredited IIS do not have a GIC. Their explicit inclusion is necessary for the accreditation or re-accreditation of IIS (led by nursing professionals).

Suggestions:

Institutional strengthening:

- Inclusion of nurses in the governing bodies and scientific committees of IIS.
- It is necessary to ensure stable and sufficient funding for GICs, both at institutional level and through competitive calls.
- Intensification calls for nurses.

Improvement of training:

- Development of specific training programmes for research nurses, ranging from research methodology to project management.
- Encouragement of PhDs in nursing and the training of new researchers.

Encouragement of collaboration:

- Creation of national and international care research networks to facilitate collaboration and knowledge sharing.
- Encouragement of GIC participation in multi-centre and coordinated projects.
- Establishment of stable consortia between different institutions or stable structures of ISCII to address common problems and generate greater scientific impact.

Dissemination and visibility:

- Development of effective communication strategies to disseminate the results of nursing research to the scientific community, health professionals and society in general.
- Encouragement of the publication of articles in scientific journals of recognised prestige.
- Promotion of the participation of care researchers in national and international congresses.

Support for research careers:

- Incorporation of research activity in the systems of evaluation and professional promotion of nurses.
- Establishment of specific professional categories for care researchers.
- Provision of mobility opportunities for care researchers to broaden their knowledge and establish new collaborations.

Suggested changes to each section of the Technical Guide for the Evaluation and Accreditation of Health Research Institutes are listed below.

Teaching and Research Nucleus

Guide item	Suggestion
1.1.2.3 There shall be a minimum of 25 accredited teaching units for specialist health education, with a minimum of 2 accredited teaching units for specialist nursing education.	No change

Governing bodies

Guide item	Suggestion
1.2.1.2 No change	The composition should appear on the website. Verification that all the institutions listed in the agreement are represented, including a nurse representing the management of the centre (school or faculty) or the department responsible for the Bachelor's Degree in Nursing on the Board of Trustees and another nurse representing the same institutions on the Governing Board.

External scientific committee

Guide item	Suggestion
1.2.3.2 No change	Verification of the existence of the minutes of the ESC, approved by its members (signature or notification of approval), including a nurse member, with the periodicity established in the regulations (excluding the minutes of extraordinary meetings to establish the periodicity).

Internal scientific committee

Guide item	Suggestion
1.2.4.1 There is an Internal Scientific Committee (ISC), Different types of researchers should be represented, including researchers in care, and gender equality principles should be respected.	No change

Scientific areas

Guide item	Suggestion
1.2.5.1 Research at the IIS is organised around scientific areas or scientific programmes, among which the scientific area of care is recognised, to which the action plan	No change

Guide item	Suggestion
1.2.5.7 The scientific area of care will have at least one emerging and/or associated care group in which the development of research careers in its area of competence will be promoted.	The action plan will provide information on how this function will be carried out. Minutes of the scientific areas' meetings in the 12 months prior to the application for accreditation to verify the development of this function.

Economic management of research and projects

Guide item	Suggestion
1.4.2.3 At least 20% of the indirect costs received each year will be dedicated to actions aimed at supporting IIS researchers, such as training, education, co-financing of contracts, IIS own projects for emerging and associated care groups, contracts for intensification of care researchers, etc.	No change

Human resources and critical mass

Guide item	Suggestion
2.2.1.2 The IIS has dedicated research space in at least one health centre or other primary care research support structure in the IIS's area of influence. There is documented evidence of the assignment of the use of these spaces to the IIS for the scientific activities of the researchers assigned to all research groups.	No change

Guide item	Suggestion
2.2.2.2 The human resources plan includes measures for recruitment, professional development and research talent, with explicit reference to the integration of clinical groups and the development of emerging and associated groups.	No change
2.2.2.18 The IIS must have a care research group.	Care research group led by a nurse with clinical and academic professionals.
2.2.2.19 The IIS has at least 2 active care research projects with own, public or private funding in the last year where the MR is a nurse.	Calculation: Number of active health services researchers with a nurse MR. IIS researchers register as of 31 December of the year preceding the application. Evaluation period: year preceding the year of application.

Training

Guide item	Suggestion
2.2.4.6 The training plan includes mentoring activities aimed at centres, and emerging and associated groups that are part of the institute or its environment.	No change
2.2.6.3 An annual scientific report, including a gender perspective, is produced, with at least the following content: RESEARCH ACTIVITY – Number of research projects awarded (competitive and non-competitive calls). – Number of scientific publications by category (original articles, reviews, etc.). Percentage of original articles in the first decile and first quartile of publications in the year of publication. – List of GPC developed by JBI in centres recognised by investén-ISCIH and implemented in IIS health centres.	No change

Research results

Guide item	Suggestion
2.3.2.10 Indicator of care research: Number of publications by IIS nurse researchers published during the last 5 years in which the IIS affiliation is mentioned.	Calculation (number of publications by IIS nurse researchers with appropriate affiliation to IIS / total number of IIS nurse publications in the evaluation period) *100 Publications to be considered: original articles and reviews in journals indexed in JCR or SJR. Period evaluated: 5 years prior to the time of evaluation. THRESHOLDS: EXCELLENT ≥ 95%; ACCEPTABLE 70-94%; DOES NOT MEET < 70%.

Training Plan

Guide item	Suggestion
3.1.2.1 The number of guidelines published in indexed journals in the last 5 years, plus the number of institutional publications in which the IIS has participated is ≥10, including implementation publications in the journal JBI.	No change
3.2.1.4 Specific research training activities for NURSES have been carried out at least once in the last 2 years.	It is necessary to documentary verify it in the memory of the IIS training plan.

Support Plans for the Dissemination of Science in Non-Scientific Areas: Role of Researchers

GT6. *Institute Partnership*. 2022.

Coordination: IiSGM

Manager: Dr. Ismael Buño. Scientific Director IiSGM.

Executive Summary

One of the main pillars of science policy is the dissemination of scientific knowledge, which is both a responsibility and a commitment of institutions and researchers.

The purpose of this report is to draw up plans to support the dissemination of science in non-scientific fields and the role of researchers in this dissemination. The aim was to establish some guidelines or recommendations for integrating this dissemination work into the activities of researchers.

Two surveys were carried out to obtain an initial analysis of the situation. One was addressed to the members of GdT6 and the other to the 35 accredited IIS. The first survey was dismissed due to low participation. The second survey received a response from 23 IIS, the results of which are presented in this report. In addition, IIS were asked to provide information and/or documentation related to the questions posed, and a significant number of IIS responded by sharing documents related to their science dissemination activities.

Among the objectives and conclusions are the creation of a repository, the identification of good practices followed by researchers in disseminating science to society, and the availability of information on research staff participating in training courses on science dissemination, as well as on the level of participation of members of society in the dissemination activities carried out. Similarly, a reference document has been produced for research staff to guide them in incorporating the perspective and dissemination to non-scientific actors and society in general at the different stages of their research activity.

Introduction

The main objective of the IIS Partnership is to create a stable space for cooperation and joint work between the Institute of Health Carlos III (ISCIII) and the accredited IIS in order to i) respond to the needs of the IIS in the dynamic environment of R&D&I; ii) to align the scientific policies of the IIS with the strategic lines of the European framework; iii) to promote cooperation between the IIS, creating synergies that increase their competitiveness; and iv) to promote the participation of the IIS in the definition of the ISCIII's lines of action.

To this end, working groups (GT) are established to address the relevant issues in this context. The composition of the working groups is based on the prioritisation sent by each of the accredited IIS. Each GT is made up of 10-11 IIS, one of which acts as coordinator for organisational purposes, to facilitate the progress of the work and, with the necessary support of the ISCIII, to lead the work carried out to achieve the proposed objectives. Participation in each GT is determined at the level of the IIS. The internal organisation of this participation in each IIS will be coordinated by its Scientific Management.

Objectives of GT6:

1. The creation of a repository of dissemination models with proven effectiveness to be made available to the entire IIS Partnership.
2. The identification of good practices.
3. The preparation of a reference document for researchers to integrate the societal perspective into their lines of action, both in planning and in carrying out and disseminating results.

Theoretical framework

The importance of science dissemination.

In the context of Responsible Research and Innovation (RRI), the dissemination of scientific knowledge is the responsibility of every researcher and every research institution, as it contributes to the democratisation of knowledge and the overall improvement of societies. It is one of the fundamental pillars of the science policies of the European Union and its Member States.

In this sense, and due to its great relevance in today's societies, the ISCIII includes these aspects among the criteria of the Technical Guide for the Evaluation and Accreditation of Biomedical or Health Research Institutes.

Thus, the scientific communication plan is taken into account (point 3.2.2 of the Guide) and it is intended (criterion 3.2.2.5.) that the number of dissemination activities towards the general public should show a progression over time (5 years are assessed) until a number of 5 annual actions is reached at the time of applying for accreditation (THRESHOLD: ACCEPTABLE 1-3, EXCELLENT ≥ 4). It is also appreciated that the IIS actively participates in the scientific dissemination activities organised by the ISCIII together with other IIS (criterion 3.2.2.6).

On the other hand, the participation of "non-scientific key actors" is another aspect of utmost relevance, which is considered in several points of the Guide and which is addressed by the GT3 of the IIS Partnership, with which we have worked in close collaboration.

Methodology

Several telematic meetings have taken place since May 2022, both between the coordination of the different working groups with the ISCIII and within this GT6. This first phase culminated in the sending of a draft consensus document to the ISCIII during the week of 15 November 2022.

In parallel, two online questionnaires were conducted using the Google Forms platform. The first questionnaire, designed as an open questionnaire for the IIS members of GT6 to present their status and best practices, had a tepid reception and was ultimately rejected due to its limited usefulness. The second questionnaire (<https://forms.gle/GqE4A2DRbGRyoERV9>) was sent to all accredited IIS and had a very acceptable response rate (23/34 IIS, 68%). The results of this questionnaire are presented in this document.

In parallel, IIS were asked to provide information and documentation on each of the questions asked. A significant number of IIS shared documents related to their science dissemination activities.

DEVELOPMENT AND RESULTS

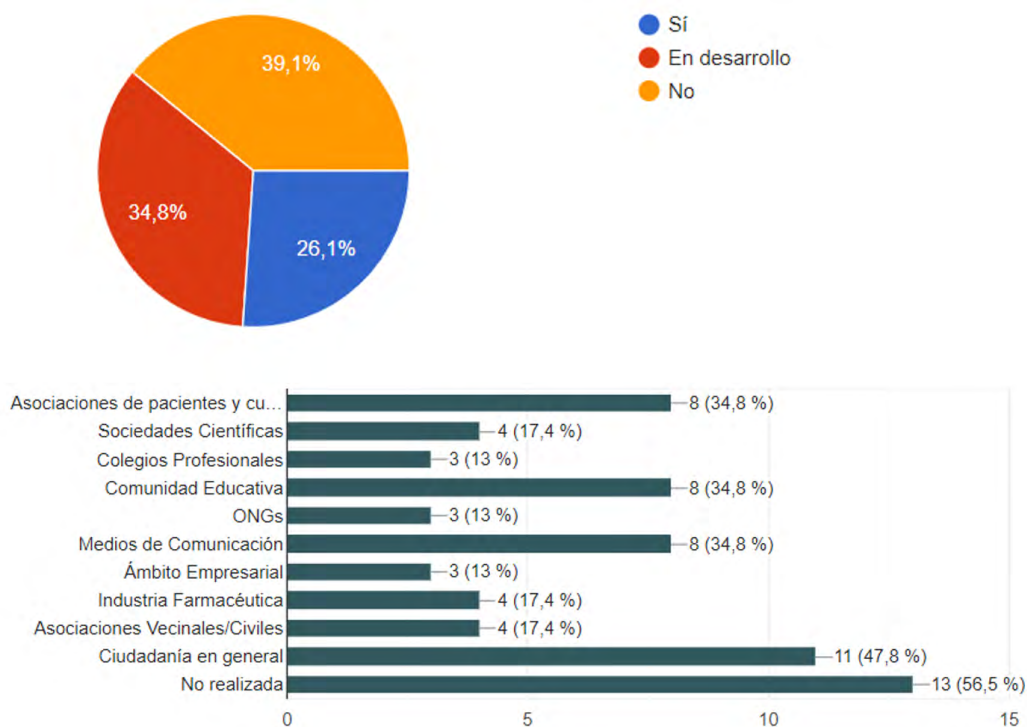
Objective 1 *The creation of a repository of dissemination models with proven effectiveness to be made available to the entire IIS Partnership.*

A repository of documentation and information provided by the various IIS that make up GT6 has been created and will be made available to all accredited IIS through the ISCIII SharePoint.

Objective 2 *The identification of good practices.*

The documentation supporting the good practices listed below can be found in the repository mentioned in Objective 1.

The Institute has a training programme for research staff in “Science Communication in Non-Scientific Fields (Scientific Dissemination)”.



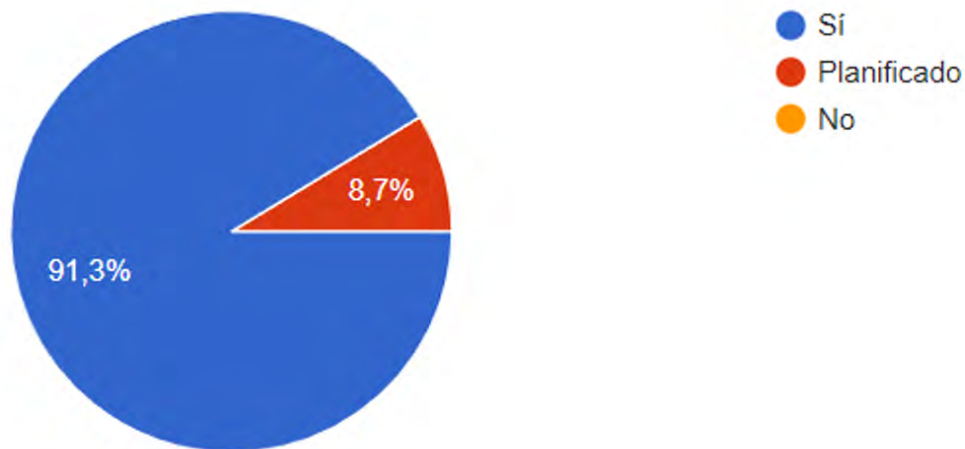
Different IIS have courses, conferences or training programmes to train research staff in the skills needed to disseminate science. The ultimate goal is to provide staff with the tools to participate successfully in dissemination activities, media interviews, public debates, events with the public, etc.

Interestingly, in some IIS, students participating in these courses carry out dissemination activities (videos, etc.) which are then disseminated through social networks.

Another interesting initiative in this line is to promote the dissemination of science by supporting science communication projects in intramural calls.

The aim of this type of action is to motivate and involve researchers in the communication and dissemination of projects and their results, to develop their communication skills and to generate new scientific interests and vocations among the public.

The Institute participates in activities aimed at society (Science Week, European Night, etc.).

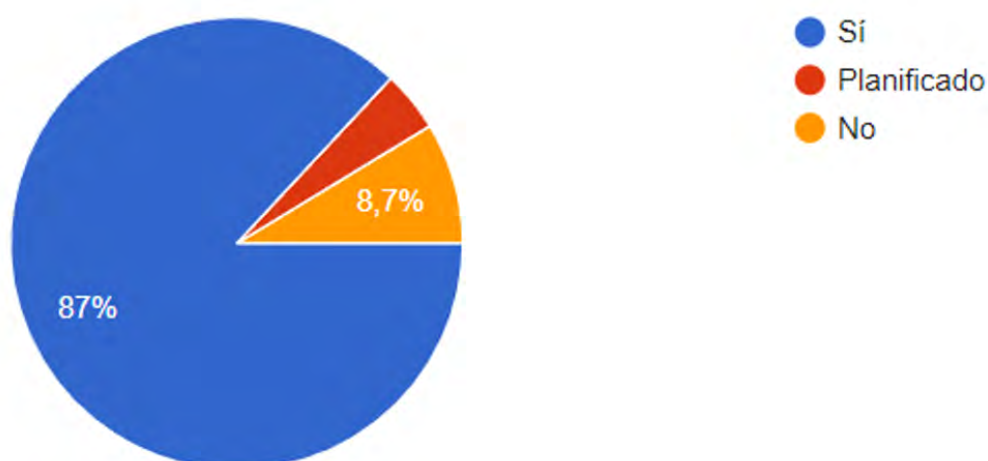


Participation in various activities aimed at society, such as Science Week, European Researchers' Night, International Women's Day, International Day of Women and Girls in Science, World Health Day, Pint of Science, Beer for Science, Science Café, University in your Neighbourhood, Science in the Neighbourhood, science photography competitions, DNA Day, etc.

In this context, there are open-door sessions, exhibitions, round tables, workshops and virtual visits, as well as sessions with specific thematic content (breast cancer, multiple sclerosis, rare diseases, etc.), discoveries recognised by the Nobel Prize in Physiology and Medicine, participation in sporting events, etc.

One IIS has created its own "mascot" to facilitate communication with society.

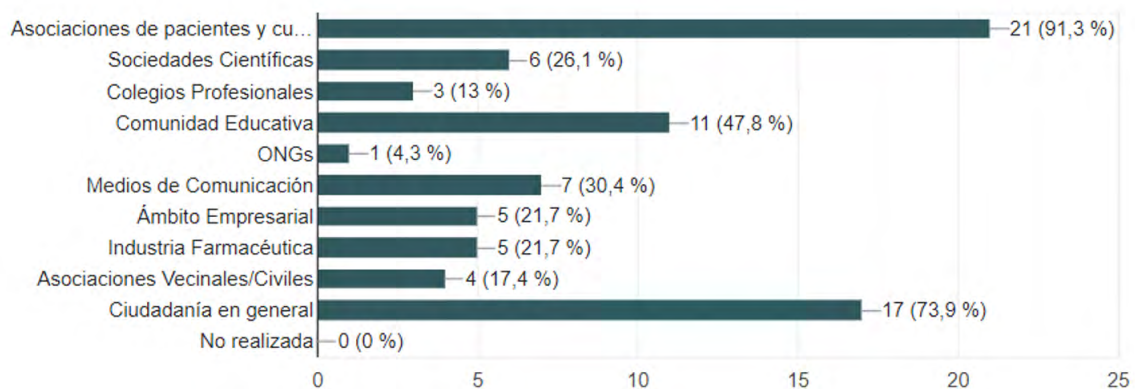
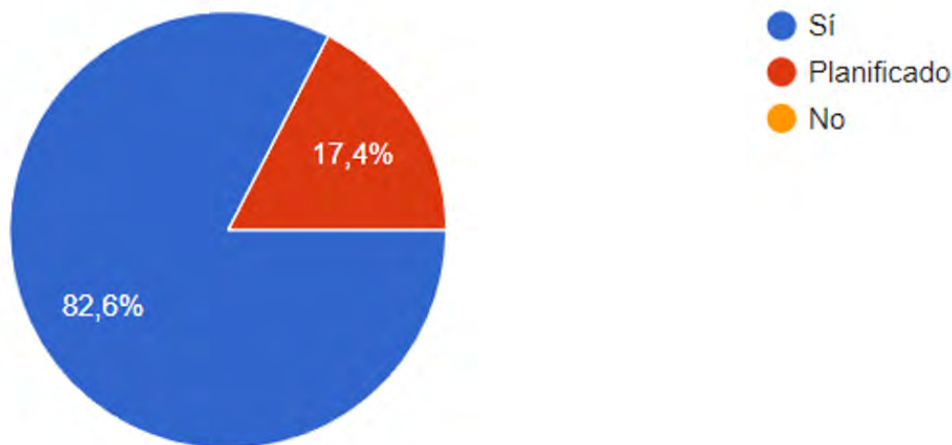
The Institute participates in activities aimed at students



Several IIS are involved in activities aimed at students at different levels. Activities are carried out for students to visit the IIS, such as some initiatives promoted by the Autonomous Community (4th ESO +

Company in the Community of Madrid, for example), with other research institutions (CSIC-IIS Scientists in Practice Programme) or local ones organised by the IIS itself. At the same time, actions are promoted for research staff to give lectures or participate in different activities in schools, student residences, etc.

The Institute organises Conferences/Seminars aimed at the general public.



IIS organise different types of activities (conferences with different presentations, thematic talks/seminars, workshops, etc.) both in their own facilities and outside (city libraries, town halls, etc.).

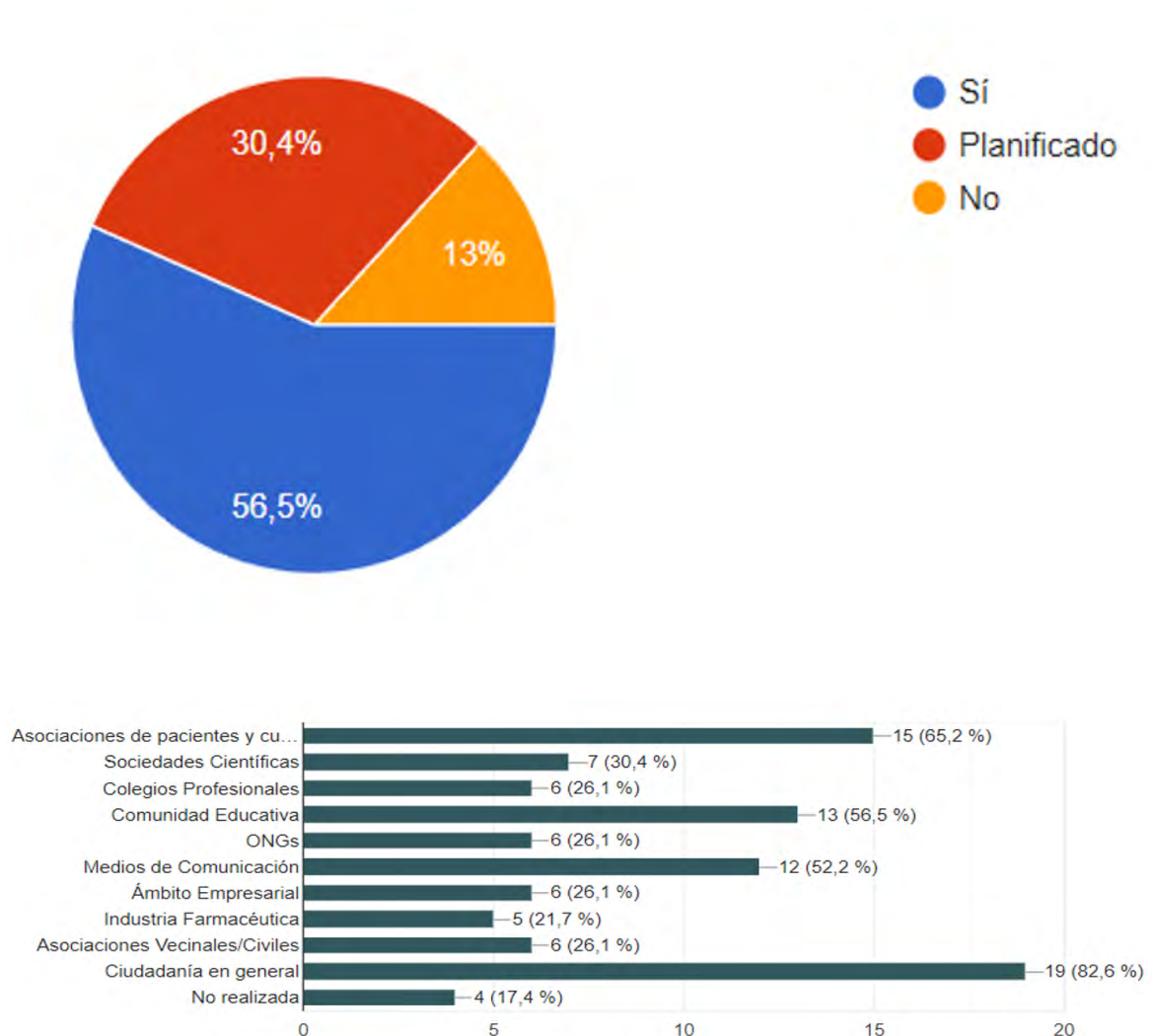
Occasionally, open online conferences and seminars are organised, to which anyone outside the institution can connect.

In some IIS, the initiative and organisation is taken by the research groups, while others have a centralised programme of activities coordinated by the IIS.

In some cases, activities are linked to the celebration of “world days” for different pathologies or related topics.

Some IIS organise activities aimed at patients or patient associations on the specific topic of interest to them.

The Institute's website has specific content aimed at the general public.



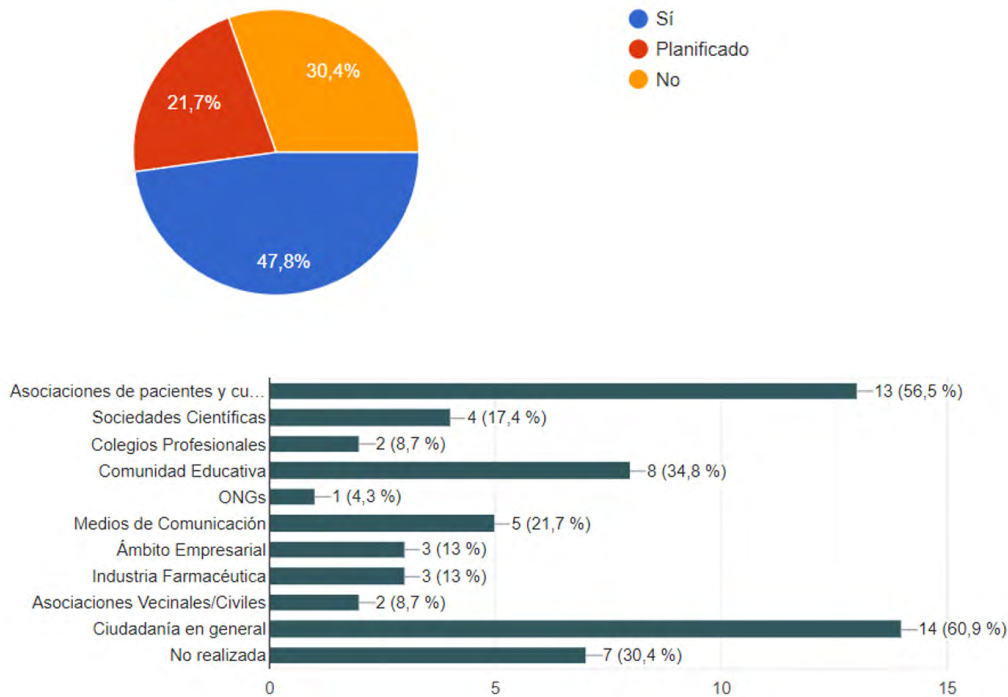
Several IIS have a dedicated section on their website with specific content aimed at the general public, with a “Communication” section where news are disseminated to all types of public, both scientific and non-scientific.

Some IIS publish on their website, as part of the regular news bulletins, a specific bulletin aimed at the business community.

Some IIS publish on their website information on different diseases and the research carried out on them at the institute aimed at the general public.

Some institutes have suggested that, in addition to publishing “lay summaries” of funded research projects, the ISCIII should also publish the final reports of these projects, asking for a “lay summary” of the objectives achieved.

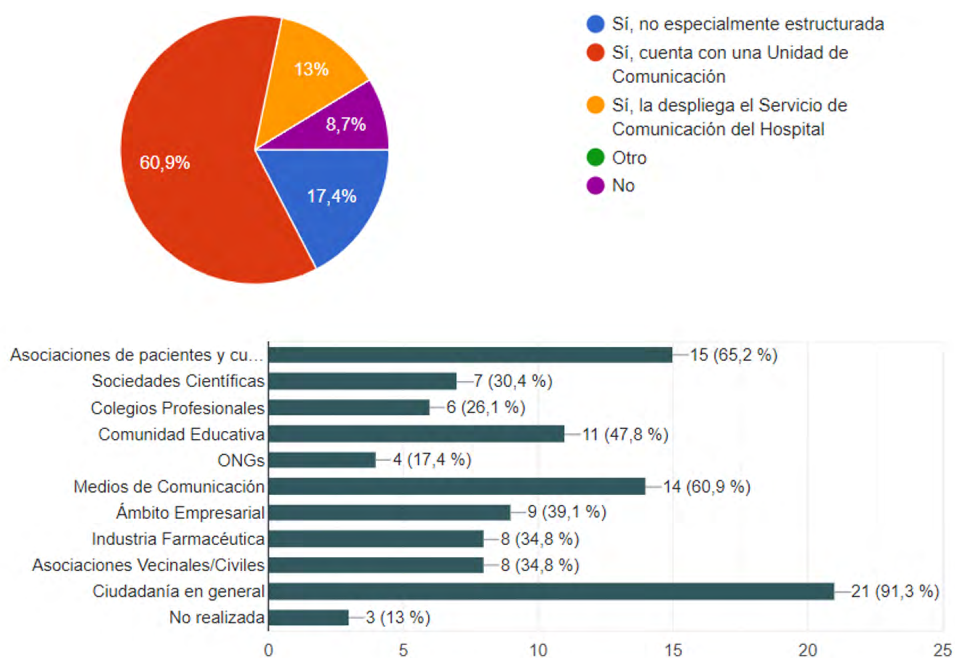
The Institute produces monographs/documents/brochures, etc. with specific content aimed at the general public.

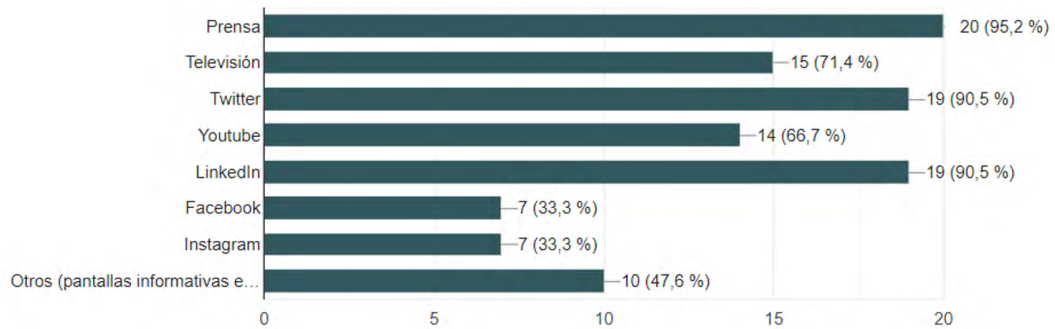


Several IIS have research groups that produce reports, monographs, documents and brochures for the general public as part of the various projects in which they are involved. In some cases, this activity is particularly relevant in the area of primary care research.

Other IIS carry out this activity centrally, designing and disseminating various materials (infographics, videos, etc.) with specific content to bring science and research activities closer to the public.

The Institute has a communication strategy with specific content aimed at the general public.



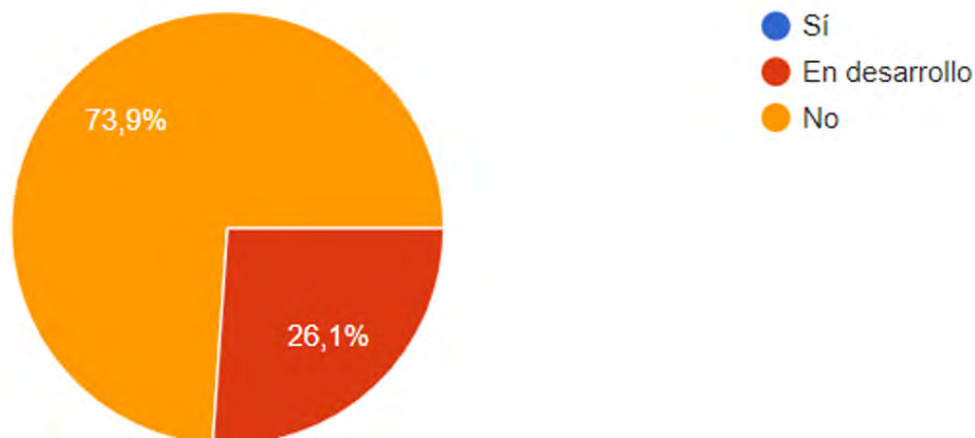


It is interesting to note that the vast majority of IIS actively develop and implement their own communication strategy, often aligned with that of the core IIS hospital. Interestingly, the majority of IIS actually have a communication unit (some accredited by the FECYT) within their own structure. A small percentage of IIS delegate their communication strategy to the hospital communication service.

It is also worth mentioning, in addition to the traditional presence in the press, especially, and television, the important presence of the IIS in social networks, among which Twitter, LinkedIn and Youtube stand out.

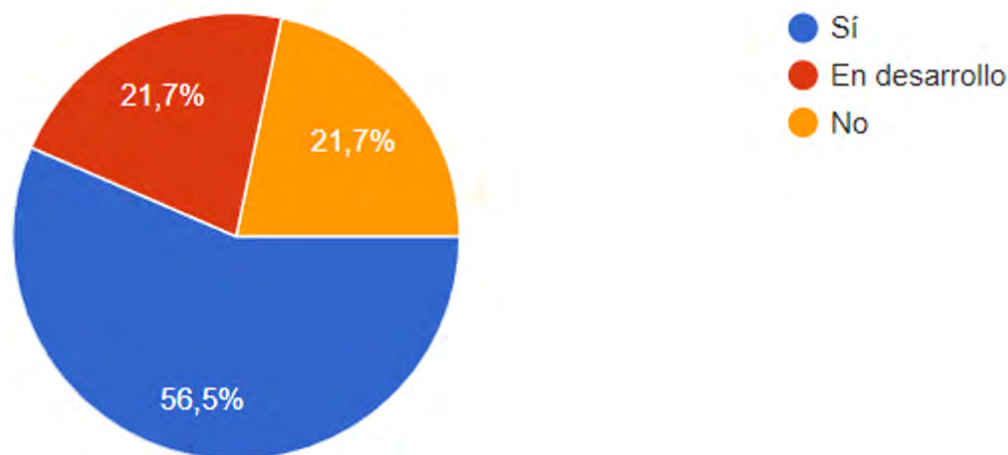
Half of the IIS also apply their communication strategy in other ways, such as disseminating information via the screen system in hospital waiting rooms, etc.

The Institute has a specific training programme for “non-scientific actors” who participate in governing bodies, advisory bodies, committees, etc.



It is striking that, despite the significant degree of development of the dissemination strategies of the different IIS, the vast majority of them do not have a training programme aimed at "non-scientific actors" integrated into the IIS environment in the context of RRI actions (see Working Group 3 – GT3, of the IIS Partnership).

The institute has tools to assess the satisfaction of the target audience of the activities.



Most IIS have tools, mainly surveys, to measure the satisfaction of participants in the different activities. Both for the research staff participating in the training courses on science dissemination and for the public participating in one of the dissemination activities carried out.

Objective 3 The preparation of a reference document for researchers to integrate the societal perspective into their lines of action, both in planning and in carrying out and disseminating results.

Due to the great heterogeneity that exists between the different IIS in terms of dissemination strategies, mechanisms and structures for their implementation, activities carried out, etc., a proposal for a document for research staff is presented below (see Appendix I), which includes the various items dealt with in this document in the form of "checklists" to facilitate the task of each IIS in adapting it to its specific needs and situation.

CONCLUSIONS AND SUGGESTIONS

Suggested structure for a "Document for Researchers"

Each Institute can include a short introduction (using the one at the beginning of the GT6-IIS Partnership Consensus Document and adapting it to the particularities of each IIS) explaining why it is important for researchers to communicate science to non-scientific actors and that the Institute offers training and activities to do so.

1. Have you completed the Institute's training programme for research staff in "Science Communication in Non-Scientific Fields (Scientific Dissemination)"?

or

Have you taken the course on Science dissemination for researchers offered by the Institute?

- Yes
- No

(Please add a short description of the course and instructions for registration)

The Institute organises a course on science dissemination for researchers once a year, where we teach you who are the non-scientific actors you can address and give you the tools to disseminate the results of your research. You can see the dates and programme here and register here.

2. Do you participate in activities aimed at society?

- Yes
- No

The Institute participates in the following activities aimed at society, in which you can also participate:

(Add the activities in which the Institute participates that are not included in the list below)

1) European Researchers' Night (more information: Madrid, Barcelona, Andalusia, etc.)

- What is it? During the European Researchers' Night, hundreds of free activities take place, bringing the work of researchers, their benefits to society and their impact on everyday life closer to the public in a fun way. All this through experiments, workshops, demonstrations, experiences, routes, theatrical performances, monologues, etc.
- When is it? Annually. The last edition was held on 30 September 2022.
- How can you register? If you are interested in taking part in the next edition, you can send us your proposal to the following address (please include your institute's email address and internal deadline).

2) Science and Innovation Week

- What is it?
The Ministry of Science and Innovation organises this activity, which includes workshops, exhibitions, guided tours, round tables and scientific routes, with the participation of specialists from all fields of knowledge, in order to show the diversity of research and its important contribution to society.
- When is it? Annually. The 22nd Science Week took place from 7 to 20 November 2022.
- How can you register? If you are interested in taking part in the next edition, you can send us your proposal to the following address (please include your institute's email address and internal deadline).

3) International Day of Women and Girls in Science

What is it? 11 February is a citizens' initiative to celebrate the International Day of Women and Girls in Science by organising activities to:

- Make visible the work of women in STEM (Science, Technology, Engineering and Mathematics) fields, thus creating female references for children that can contribute to the choice of these fields as professional careers.
- Understand the different factors that influence the current situation of women in STEM, in order to promote practices that lead to their elimination and to achieve gender equality in science.

When is it? The last edition was held on 11 February 2023.

How can you register? If you are interested in taking part, you can send us your proposal to the following address (please include your institute's email address and internal deadline).

4) San Sebastian Innovation Week (WeeINN)

What is it? Launched for the first time in 2013, the Innovation Week aims to make the city and its ecosystem's commitment to innovation visible from the perspective of different actors, sectors and groups. With a specific theme for each edition, it has an ambitious programme that seeks to create spaces for reflection and knowledge in different spaces, with formal and informal activities and different themes. All this in order to strengthen the city's brand and position it as a centre of innovation, from the local to the international level.

When is it? Annually. The last edition was held from 22 to 28 October 2022.

How can you register? If you are interested in taking part, you can send us your proposal to the following address (please include your institute's email address and internal deadline).

5) Barcelona Science Festival

What is it? It is the great encounter between citizens and scientific culture, open to the public of all ages, with a wide range of formats to experience science at first hand: experiments, installations, games, workshops, demonstrations, shows, debates, "micro-talks", itineraries and guided tours, among others.

When is it? Annually. The last edition was held on 28 and 29 May 2022.

How can you register? If you are interested in taking part, you can send us your proposal to the following address (please include your institute's email address and internal deadline).

3. Do you participate in activities aimed at students?

- Yes
- No

The Institute participates in the following activities aimed at students, in which you can also participate: (Add the activities aimed at students in which the Institute participates that are not included in the list below)

4th ESO+Business Programme (More information: Madrid)

– What is it? The 4th ESO+Business Programme is an educational programme of the Community of Madrid aimed at students in the 4th year of compulsory secondary education in the schools participating in the programme. It is being carried out on a voluntary basis in a growing number of schools, with the aim of bringing the education system and the world of work closer together and help the students to make better choices about their academic and professional futures through educational stays in companies and institutions.

The Institute participates by offering stays of 3, 4 or 5 consecutive school days between March and May each year, depending on the edition.

– When is it? Annually.

– How can you register? If you are interested in taking part in the next edition, you can send us your proposal to the following address (please include your institute's email address and internal deadline).

Escolab (Barcelona)

- What is it? This programme offers free scientific activities, workshops and guided visits for secondary school, high school and professional education students, allowing them to discover the great diversity of laboratories and to come into direct contact with their multidisciplinary teams and their lines of research.
- When is it? The activities will take place from September.
- How can you register? The registration period for the draw was from 9 to 16 September 2022: <https://escolab.bcn.cat/es/bookings>. If you are interested in taking part in the next edition, you can send us your proposal to the following address (please include your institute's email address and internal deadline).

4. Do you participate in conferences/seminars aimed at the general public?

- Yes
- No

(Add the conferences organised by the Institute and instructions on how to participate in the conferences and seminars).

If you are interested in taking part or you would like to make your own proposal, you can send it to us at the following address (please include your institute's email address and internal deadline).

5. Do you participate in the development of general public-oriented content for the Institute's website?

- Yes
- No

You can see the web contents addressed to the public by clicking here

(Insert link to the Institute's website)

How can you participate? If you have an idea, activity or result that you would like to disseminate, send it by email to (insert e-mail address of the Institute) so that we can evaluate and disseminate it.

6. Do you participate in the preparation of monographs/documents/brochures, etc. of the Institute with contents addressed to the general public?

- Yes
- No

(Add examples and instructions to let them know how they can participate)

7. Are you aware that the Institute has a communication strategy with specific content aimed at the general public?

(Insert link to the Institute's communication strategy)

8. Do you know that the Institute is present in the media and on social networks and that you can send us your news?

- Yes
- No

- Add links to examples of the Institute's press and TV appearances.
- Add links to the Institute's Social Networks:
 - Twitter profile
 - Youtube profile
 - LinkedIn profile
 - Facebook profile
 - Instagram profile

How can you participate? If you have an idea or result that you would like to disseminate, send it by email to (insert e-mail address of the Institute) so that we can evaluate and disseminate it.

9. Do you participate in the specific training programme for “non-scientific actors” who participate in governing bodies, advisory bodies, committees, etc.

- Yes
- No

(Add the training that is carried out in the Institute and instructions on how to participate)

10. Have you completed the researcher satisfaction survey

- Yes
- No

Finally, we encourage you to fill in the following satisfaction survey and give us your ideas on how we can improve the dissemination of science or how you would like to disseminate science to non-scientists.

11. Suggestion Box

You can send us your suggestions, activities and ideas that you would like to carry out to disseminate science to society to the following email address: (insert institute email)

APPENDIX

APPENDIX I. Members of the working group.

IIS RESEARCHERS' CAREERS

- IdISBa. Miquel Fiol y Asunción Sánchez (Coordination)
- IGTP. Jordi Barretina y Carles Esquerra
- IMIBIC. María del Mar Malagón
- Ibs.Granada. María José Sánchez
- VHIR. Montserrat Giménez Prous y Joan Comella
- IMIM. Joaquín Arribas
- IdiPAZ. Eduardo López-Collazo
- IDISSC. Elena Urcelay
- Biodonostia. Amaia Preduzo y Arantxa Abad
- INCLIVA. Andrés Cervantes
- IISGM. Ismael Buño
- IBSAL. Raquel Carnicero

STRATEGIES TO FACILITATE THE DEVELOPMENT OF OPEN ACCESS (OA) IN IIS: THE HEALTH INSTITUTIONAL REPOSITORY OF ISCIII.

- IBIMA– BIONAND PLATFORM (Coordination)
- LA FE
- BIODONOSTIA
- IBIS
- IDIVAL
- LA PRINCESA
- IIS PDH
- SANT PAU
- IIS FJD
- IRB LLEIDA
- ISABIAL
- IISGM

GENDER PERSPECTIVE

- Gabriel Capellá; Beatriz Pinilla – IDIBELL (Coordination)
- M. Laura García; Clara López – IRYCIS

- Carmen Ayuso; Victoria del Pozo – IIS-FJD
- María Lorenzo; Raquel Carnicero – IBSAL
- Elena Urcelay; Susana Sánchez – IdISSC
- M^a Rosario Luquin – IdiSNA
- Marcos López – IDIVAL
- Máximo Vento – IIS La Fe
- Salvador Marcus; Miquel Fiol – IdISBA

IIS ACTIVITY MONITORING SYSTEM: REVIEW OF INDICATORS

- IRYCIS: M^a Laura García Bermejo, Laura Barreales, Ana Moreno Bofarull y Noelia Álvarez (Coordination).
- IBIS: Rafael Fernandez-Chacón and José Cañón Campos
- I+12: Joaquín Arenas Barbero, Mar López Martín, María Lopez Berlanga and Isabel de Mier Barragán.
- IMIBIC: Pablo Pérez Martínez, Álvaro Granados del Río, Estefanía Azcona Corrales, M^a del Mar Malagón and Lola Ruíz Polo.
- IDIS: José Castillo Sánchez, Isabel Lista García, José Ramón Castro Ruibal and Yolanda Liste Martínez.
- BIOCRUCES: Luis Castaño González, María Luz del Valle Ortega, Eunata Arana Arri and Tatiana Izquierdo García.
- IMIB: Pablo Ramírez Romero, Fuensanta Martínez Lozano, Ángel Esteban Gil, María del Mar Vázquez de Parga and Marta Jovar Aguilar.
- IIS ARAGON: Ángel Lanas Arbeloa and Óscar López Lorente
- IDIPHISA Mariano Provencio Pulla, Jesús Rey Jiménez and Cristina Avedaño Fernández.
- IDIBELL: Anna Garcés Aparici and Beatriz Pinilla Romero.
- IBIMA: Francisco José Tinahones Madueño, José Miguel Guzmán de Damas, María Marín Martínez and Eva Pena Gatón.
- INIBIC: Francisco Javier Blanco García, Patricia Rey Pérez, Natalia Cal Purriños and Diego Otero Tomera.
- VHIR: Joan Comella Carnicé, Montserrat Giménez Prous, Núria Gavaldá and Jordi Moretón

INTERNATIONALISATION OF IIS

- INCLIVA (Coordination): Andrés Cervantes (General Director) and Marta Peiró (Assistant Director INCLIVA) Ana Ferrer Albero (International Programmes)
- IdISSC
- IIS BIOCRUCES
- IMIM
- IRB LLEIDA

- IDIS:
- IMIBIC
- IDIPHIM
- IRYCIS
- IGTP
- IMIB

DATA MANAGEMENT PLAN

Subgroup 1

- IIS ARAGON: Sergio Cervero (Coordination)
- ISABIAL: Óscar Moreno, Luis Miguel Valor, Carla Ordiñana (Coordination)
- ISPA: Ángel Luis Mones Iglesias (Coordination)
- IDIPHISA: Jesús Rey Jiménez, Cristina Escudero Gómez (Coordination)
- IR-HUVH: Álex Sánchez (Coordination)
- IIS LA PRINCESA: Isabel Barrio, M^a Jesús Bono (Coordination)
- IDIBAPS: Juan Abolafia (Coordination)

Subgroup 2

- IIS ARAGON: Javier Aragón (Coordination)
- IIS SANT PAU: Javier Aragón (Coordination)
- ISPA: Carolina Pinin Osorio, Diego Otero (Coordination)
- IDIBAPS: Michela Bertero (Coordination)
- INIBIC: Alexandre De la Fuente (Coordination)
- IDIVAL: Juan Manuel Medina (Coordination)
- IR-HUVH: Álex Sánchez (Coordination)

Subgroup 3

- IIS ARAGON: Sergio Cervero (Coordination)
- INIBIC: Alexandre De la Fuente, Diego Otero (Coordination)
- ISPA: Roberto Fernández (Coordination)
- IIS LA PRINCESA: Isabel Barrio (Coordination)
- IDIBAPS: Gemma Pascual (Coordination)

INVOLVEMENT OF NON-SCIENTIFIC KEY ACTORS IN IIS ACTIVITIES

- IDISNA: Nicolás Martínez Velilla (Scientific Director) and Natalia Cal Purriños (Managing Director)

- IISFJD: Victoria del Pozo Abejón (Scientific Deputy Director) and Ana Rubio Araiz (Assistant Scientific Director)
- IBIMA: Francisco Tinahones Madueño (Scientific Director) and IBIMA: Jose Miguel Guzmán de Damas (Managing Director)
- IDIPAZ: Paloma Gómez Campelo (Deputy Technical Director) and: Lucía Medina Royo (Communication Manager)
- IR-HUVH: Macarena Herranz Iturbide (Manager of the Technical Secretariat Unit)
- IIS BIODONOSTIA: Olatz Arrizabalaga Garde (Scientific Coordination)
- IIS BIODONOSTIA: Maider San Torcuato Labaien (Technician at the Innovation Support Unit)
- ISPA: Victoria Álvarez Martínez (Scientific Director)
- IIS i+12: María López Berlanga (Quality, Strategic Planning and Innovation Coordinator)
- IMIBIC: Isabel de Castro Burón (Head of Communication) and Inmaculada Varo Urbano (Head of Training)
- IIS LA FE: Anna Juan Roch (Communication Coordinator)
- ibs.GRANADA: Coordination: María José Sánchez Pérez – Coordinator (Scientific Director), José Antonio Castilla Alcalá (Assistant to the Scientific Director), José Juan Jiménez Moleón (Assistant to the Director), Sarah E. Biel Gleeson (Executive Director), Dafina Petrova (Postdoctoral Researcher) and Francisco Jesús Salcedo Avilés (Head of the Technical Secretariat).

INTEGRATION OF THE ECONOMIC MANAGEMENT OF SCIENTIFIC ACTIVITIES OF THE RESEARCH GROUPS ATTACHED TO THE IIS

- IDIBAPS: Elias Campo Güerri (Scientific Director) and Rosa Vilavella Gasull (Managing Director)
- IMIB: Pablo Ramirez Romero (Scientific Director) and Maria Fuensanta Martínez Lozano (Managing Director)
- IIS LA PRINCESA: Francisco Sánchez Madrid (Scientific Director) and Rosario Ortiz de Urbina (Managing Director)
- IDIVAL: Marcos López Hoyos (Scientific Director) and Francisco Galo Peralta Fernández (Managing Director)
- IMIM: Joaquín Arribas López (Scientific Director) and Andreu Fort Robert (Managing Director)
- ibs.GRANADA: Maria José Sánchez Pérez (Scientific Director)
- IDISNA: Nicolás Martínez Velilla (Scientific Director) and Natalia Cal Purriños (Managing Director)
- INIBIC: Maria del Mar Castellanos Rodrigo (Scientific Director) and Patricia Rey Pérez (Managing Director)
- IBIS: Rafael Fernández Chacón (Scientific Director) and José Cañón Campos (Managing Director)
- IDIBELL: Gabriel Capellá Munar (General Director) and Cristina Mayordomo Tella (Assistant to the Scientific Director)

INTEGRATION OF PRIMARY CARE IN HEALTH RESEARCH INSTITUTES

- IdISBa (Joan Llobera and Oana Bulilete) – COORDINATION.
- I+12: Isabel de Mier
- IiSGM: Ismael Buño Borde (Scientific Director), Maria Isabel del Cura González, Thierry Bardinet (Managing Director)
- IDIPAZ: Lucía Medina Royo (Communication Manager) and Raúl Román Cañizares (Documentalist)
- IIS Biodonostia: Itziar Vergara Mitxetorena (Scientific Director) and Arantza Abad Alba (Managing Director)
- ISPA: Victoria Álvarez (Scientific Director)
- GTP: Julia García Pardo (Scientific Deputy Director) and Pere Torán Monserrat
- IIB SANT PAU: Miriam Ors Griera (Assistant to the Scientific Director)
- IBIMA: Jose Miguel Guzmán de Damas (Managing Director)
- IDIS: Maria de la Luz Couce Pico (Scientific Director)
- IIS ARAGÓN: Ángel Lanas Arbeloa (Scientific Director)

INTEGRATION OF HEALTHCARE RESEARCH INTO HEALTH RESEARCH INSTITUTES

- ISABIAL: María Isabel Orts Cortés (COORDINATION) and Manuela Domingo Pozo
- INCLIVA: Evelin Balaguer López and Marta Peiró Signes
- IRB LLEIDA: Joan Blanco Blanco and Esther Rubinat Arnaldo
- IdISSC: Ismael Ortuño Soriano and Daniel Muñoz Jiménez
- IIS ARAGON: Delia González de la Cuesta
- IBIS: Marta Lima Serrano and Ana María Porcel Gálvez
- IDIVAL: Sendoa Ballesteros Peña
- IRYCIS: Patricia Carrasco Rodríguez
- IBSAL: Verónica Sánchez Romero

SUPPORT PLANS FOR THE DISSEMINATION OF SCIENCE IN NON-SCIENTIFIC AREAS: ROLE OF RESEARCHERS

- IiSGM (Coordination)
- IISFJD
- IIS LA FE
- IMIB
- IBIS
- IBIMA
- IDIPAZ

- IdISBA
- IBSAL
- IDIBELL.

THE WORK WAS ALSO CARRIED OUT IN CLOSE COLLABORATION WITH “GT3 – INVOLVEMENT OF NON-SCIENTIFIC KEY ACTORS IN IIS ACTIVITIES”

List of related people:

- Miquel Fiol. IDISBA Scientific Director
- Daniel Horacio. IDISBA
- Cristina Casasnovas Riera IDISBA
- Ana Coloma IDIPAZ
- Paloma Gómez Campelo IDIPAZ
- FJ Tinahones IBIMA
- JM Guzmán IBIMA
- Ana Rubio IISFJD
- Carmen Ayuso IISFJD
- Sonia Galdón IIS LA FE
- Pablo Ramírez Romero. IMIB Scientific Director
- IMIB Accreditation
- Rafael Fernández Chacón IBIS
- José Cañón IBIS
- Sabina Pérez Vicente IBIS
- IBSAL Managing Director
- IBSAL Secretariat
- Raquel Carnicero IBSAL
- José Manuel Menchón IDIBELL
- Magda Martín IDIBELL
- Jordi Lanuza IDIBELL
- Joan Durán IDIBELL
- Ismael Buño IiSGM
- Thierry Bardinet IiSGM
- IiSGM Scientific Management
- M^a José Sánchez. As coordinator of GT3 IBS Granada

GENDER PERSPECTIVE



Foro de Institutos de Investigación Sanitaria

Grupo de trabajo GT4 Perspectiva de género

El grupo de trabajo en Perspectiva de Género pretende recopilar información relevante de los Institutos de Investigación Sanitaria en cuanto a los aspectos relacionados con la perspectiva de género y la igualdad de oportunidades. Esta información permitirá al grupo de trabajo hacer un análisis de la situación de partida para identificar retos de futuro.

Agradecemos de antemano su colaboración, y es por ello que le solicitamos si pudiese dedicar 15 minutos a contestar este cuestionario.

* Obligatoria

Datos sobre la institución

1. Nombre completo de la institución *

2. Nombre y apellidos de la persona que responde el cuestionario *

3. Cargo que ocupa *

4. Correo electrónico de contacto *

5. Indique el año de creación de su institución *

6. Indique la Comunidad Autónoma en la que se ubica la Institución *

Presencia y liderazgo femenino

7. Indique el número de personas que forman parte de la institución *

* Se consideran los datos de la anualidad 2020

** Se considera todo el personal vinculado al instituto, ya sea de forma contractual o no

8. Indique el porcentaje de mujeres de su institución, referido al total de la pregunta anterior *

- 0 a 10%
- 11 a 20%
- 21 a 30%
- 31 a 40%
- 41 a 50%
- 51 a 60%
- 61 a 70%
- 71 a 80%
- 81 a 90%
- 91 a 100%

9. ¿Está la Gerencia del Hospital, la Presidencia del Patronato o cargo equivalente actualmente ocupado por una mujer? *

- Sí
- No

10. En caso negativo, ¿lo ha estado alguna vez?

- Sí
- No

11. En caso afirmativo, ¿es la primera vez?

- Sí
- No

12. Indique el número de años que el cargo ha estado o lleva ocupado por una mujer

13. Observaciones o comentarios a la pregunta 9, si lo considera

14. ¿Está la Dirección Científica del IIS o cargo equivalente actualmente ocupado por una mujer?

*

Sí

No

15. En caso negativo, ¿lo ha estado alguna vez?

Sí

No

16. En caso afirmativo, ¿es la primera vez?

Sí

No

17. Indique el número de años que el cargo ha estado o lleva ocupado por una mujer

18. Observaciones o comentarios a la pregunta 14, si lo considera

19. ¿Está la Dirección de la Fundación de Investigación o cargo equivalente actualmente ocupado por una mujer? *

Sí

No

20. En caso negativo, ¿lo ha estado alguna vez?

Sí

No

21. En caso afirmativo, ¿es la primera vez?

Sí

No

22. Indique el número de años que el cargo ha estado o lleva ocupado por una mujer

23. Observaciones o comentarios a la pregunta 19, si lo considera

24. Indique por favor el porcentaje de mujeres en puestos de responsabilidad: *

	0-20%	21-40%	41-60%	61-80%	81-100%	No aplica
Patronato	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Subdirección Científica	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Consejo Rector	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Responsables de grupos de investigación	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Jefaturas de Servicio Hospitalario	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Investigadores/as Principales	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Comité Científico Externo	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Comité Científico Interno	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Comisión de Innovación	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Comisión de Formación	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Comisión de Calidad	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Comisión de Comunicación	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

25. Si su institución tiene algún órgano relevante distinto de los indicados anteriormente (Comisión Delegada, Comité Ético, etc) por favor especifíquelo a continuación, indicando el porcentaje de mujeres

Políticas de igualdad de oportunidades

26. ¿Existe en su institución actualmente una Unidad/Agente/Responsable de Igualdad? *

Sí

No

27. En caso de haber respondido "NO" a la pregunta anterior, ¿tiene previsto su institución crear a corto plazo una figura dedicada al fomento de iniciativas de igualdad?

Sí

No

28. ¿Existen en su institución políticas o iniciativas destinadas a la igualdad de trato y oportunidades entre mujeres y hombres? *

Sí

No

29. En caso afirmativo, ¿de qué tipo?

Políticas de Recursos Humanos

Conciliación laboral, personal y familiar

Visibilización de liderazgo femenino

Formación en materia de igualdad

Lenguaje inclusivo

Otras

30. Especificar a continuación otras políticas o iniciativas que haya implementado su institución

31. ¿Considera que la maternidad afecta de algún modo a la carrera profesional de las investigadoras en su institución? *

Sí

No

32. En caso afirmativo, especifique por favor en qué sentido y qué acciones emplea su institución para intervenir

33. ¿Los comités de selección de personal son en su institución siempre mixtos y paritarios? *

Sí

No

34. ¿Dispone en su Institución de un Plan de Igualdad adaptado al RD-Ley 6/2019 de 1 de marzo de 2019, de medidas urgentes para garantía de la igualdad de trato y oportunidades entre mujeres y hombres en el empleo y la ocupación? *

Sí

No

No, pero se encuentra en proceso de adaptación

35. ¿Se ha realizado alguna vez en su institución una auditoría retributiva con perspectiva de género (RD 902/2020, de 13 de octubre)? *

Sí

No

36. ¿Se ha postulado su institución o ha obtenido alguna vez el Distintivo de Igualdad en la Empresa (DIE)? *

Sí

No

37. ¿Estaría interesada su institución en participar conjuntamente con otras instituciones similares en iniciativas de igualdad? *

Sí

No

Formación con perspectiva de género

38. ¿Desarrolla su institución actividades formativas de algún tipo? *

- Sí
- No

39. En caso afirmativo, indique por favor:

	0-20%	21-40%	41-60%	61-80%	81-100%
% de mujeres en el alumnado de estas actividades	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
% de mujeres en el profesorado de estas actividades	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
% de mujeres en conferenciantes y ponentes	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

40. ¿Realizan o han realizado actividades específicas de formación en materia y sensibilización de género en su institución? *

- Sí
- No

41. En caso afirmativo, ¿con qué frecuencia?

- Mensualmente
- Trimestralmente
- Anualmente
- Otras

42. Especificar aquí en el caso de "Otras frecuencias"

Perspectiva de género en la investigación y la innovación

44. Como centro de investigación sanitaria, ¿tienen en cuenta aspectos de género de algún tipo en los estudios y proyectos de investigación e innovación realizados, incluidos los ensayos clínicos? *

- Sí
- No
- NS/NC

45. Si ha respondido "Sí" en la pregunta anterior, por favor especifique

46. ¿Se incluyen las variables sexo y género en las distintas fases (planteamiento de la hipótesis, metodología y análisis de resultados) de los proyectos de investigación e innovación que desarrolla su institución? *

- Sí
- No
- NS/NC

47. ¿Se desarrollan en su institución proyectos de investigación y/o innovación enfocados en la salud de la mujer? *

- Sí
- No
- NS/NC

INTERNATIONALISATION OF IIS

APPENDIX II Survey model(s) or template(s). Excel with the form filled in by the IISs is attached.

DATA MANAGEMENT PLAN

1. What is the profile of the person carrying out the survey?
 - Researcher
 - Management staff
 - Support staff (data manager, ...)
 - Other (specify)
2. Is there a person responsible for data management at your institution?
 - Yes
 - No
3. If yes, what is the profile of this person?
 - Researcher
 - Management staff
 - Support staff (data manager, ...)
 - Other (specify)
4. Does the institution's training offer include training in data management?
 - Yes
 - No
 - Don't know
5. If yes, for which staff? (more than one may be selected)
 - Predoctoral Researcher
 - Postdoctoral Researcher
 - Senior Researcher
 - Support Technicians
 - Management staff
 - Other (specify):
6. In what areas does the centre provide training related to data management? (more than one may be selected)
 - General data management training
 - Specific training on ethical aspects of data management
 - Specific training on the implementation of data management plans
 - Specific training on tools for implementing data management plans
 - Specific training on data storage and retention
 - Other:

7. What is the format of the training offered? (more than one may be selected)
 - o Course of 10 hours or less
 - o Course of more than 10 hours
 - o Seminar
 - o Practical workshops
 - o Other (specify):
8. Is there any training you have received that you would like to highlight (from the Institute or another institution)?
 - o Free text
9. What training do you consider to be a priority in relation to data management? (more than one may be selected)
 - o General data management training
 - o Specific training on ethical aspects of data management
 - o Specific training on the implementation of data management plans
 - o Specific training on tools for implementing data management plans
 - o Specific training on data storage and retention
 - o Other:
10. Who would the training be aimed at? (more than one may be selected)
 - o Predoctoral Researcher
 - o Postdoctoral Researcher
 - o Senior Researcher
 - o Support Technicians
 - o Management staff
 - o Other:
11. What format should the training take? (more than one may be selected)
 - o Course of 10 hours or less
 - o Course of more than 10 hours
 - o Seminar
 - o Practical workshops
 - o Other (specify):
12. We welcome any further considerations or comments.
 - o Free text

Involvement of non-scientific key actors in IIS activities

The main objective of the IIS Partnership is to create a stable space for cooperation and joint work between the ISCIII and the accredited IIS in order to respond to the needs of the IIS, align their scientific policies with the strategic lines of the European framework, promote cooperation between the IIS creating synergies that increase their competitiveness; and promote the participation of the IIS in the definition of the ISCIII's lines of action.

Within the framework of the Partnership, a working group has been set up to involve non-scientific key actors in the IIS. The following entities participate in this working group: IDISNA, IIFJD, IBIMA, IDIPAZ, IIS BIODONOSTIA, ISPA, i+12, IMIBIC, IIS LA FE, IR-HURVH and ibs.GRANADA as coordinating IIS.

In order to analyse the situation and identify good practices, the working group has developed this questionnaire, which complements the quantitative information available on the IIS website.

Thank you very much for your collaboration!

Contact Details

First name and surname

.....

Email

.....

Phone

.....

Affiliation details

Name of the research institute you belong to

.....

Autonomous Community

.....

Situation and good practice analysis

Does your Institute's website provide information on mechanisms for citizen participation?

a) Yes

Please provide the specific web link

b) No

Which institutions or entities could be involved as non-scientific key actors in your institute? (Please select as many as you consider)

- a) Scientific societies.
- b) Patient and caregiver associations.
- c) NGOs
- d) Media.
- e) Business sector
- f) Pharmaceutical industry.
- g) Educational community.
- h) Trade Unions
- i) Professional associations.
- j) Neighbourhood associations, federations and civil associations.
- k) Other.

Please specify which ones.

Of those considered above, which one(s) is/are currently involved in your institute as a non-scientific key actor?

(Please select as many as you consider)

- a) People from scientific societies.
- b) People from patient and caregiver associations.
- c) People from NGOs.
- d) People from the media.
- e) People from business.
- f) People from the pharmaceutical industry.
- g) People from the educational community.
- h) People from trade unions.
- i) People from professional associations.
- j) People from neighbourhood associations, federations and civil associations.
- k) Other.

Please specify which ones.

l) There are no non-scientific key actors in my institute.

How have non-scientific key actors been involved in your Institute?

(Select the ones you consider)

a) By personal invitation from the governing bodies:

– Governing Council

– Scientific Direction

– Management

b) At the proposal of the working groups.

c) At the proposal of the research groups.

d) At the request of the non-scientific actor.

e) Other.

Please specify which ones.

Please indicate the level of contribution of non-scientific key actors in your institute.

(Please select as many as you consider)

a) Participation in the prioritisation of the research lines/areas of the Joint Science Project.

Please indicate how.

b) Participation in the design of the Strategic Plan.

Please indicate how.

c) Participation in attracting resources.

Please indicate how.

d) Participation in the governing bodies.

Please indicate which ones.

e) Participation in working committees.

Please indicate how.

f) Participation in the design and development of research projects.

Please indicate how.

g) Participation in the assessment of the activities of the Institute's own plan.

Please indicate how.

h) Participation in the dissemination of research results.

Please indicate how.

i) Other forms of participation.

Please indicate which ones and how.

If you selected “f) Participation in the design and development of research projects” in the previous question, please indicate how they were involved.

(Please select as many as you consider)

- a) Non-scientific key actors were informed.
Please indicate how.
- b) Non-scientific key actors were consulted.
Please indicate how.
- c) Non-scientific key actors were involved.
Please indicate how.
- d) Co-creation activities have been carried out with non-scientific key actors.
Specify which ones.

Does your institute have a plan for the translation of scientific results into the clinical practice and the productive sector that includes actions to involve non-scientific key actors?

- a) Yes
- b) No.

What kind of training activities have been organised by your Institute for non-scientific key actors?

(Please select as many as you consider)

- a) Training activities on participation in research.
Please specify which ones.
- b) Training activities on science communication.
Please specify which ones.
- c) Training activities on co-creation in scientific research.
Please specify which ones.
- d) Training activities for the elaboration of specific documentation.
- e) Organisation of events and/or conferences aimed at non-scientific key actors.
- f) Other.
Please specify which ones.
- g) No training activities have been carried out

If you carry out any of the above activities, how often do you carry them out in your institute?

(Please select as many as you consider)

- a) Every semester
- b) Once a year
- c) Every two years

- d) Occasionally.
- e) Other.

Please specify which ones.

Please indicate the public participation channels used by your institute to enable the participation of non-scientific key actors

(Please select as many as you consider)

- a) Through contact forms.
- b) Through social networks.
- c) Open days.
- h) Specific forums.

Please specify which ones.

- d) Other.

Please specify which ones.

Does your institute have tools to assess the satisfaction of non-scientific key actors who have participated in the research activity, in its different phases?

(Please select the one you consider)

- a) Yes.
- b) No.

If you answered yes to the previous question, please indicate which tool you have used and how often you assess it.

.....

Desirable good practices in the IIS in relation to the involvement of non-scientific key actors

Please refer to other good practices promoted by the IIS in relation to the involvement of non-scientific key actors

.....

Please comment on the completion of the questionnaire and make any suggestions regarding the involvement of non-scientific key actors in the IIS.

.....

INTEGRATION OF THE ECONOMIC MANAGEMENT OF SCIENTIFIC ACTIVITIES OF THE RESEARCH GROUPS

IIS Survey model or template attached

ENCUESTA GRUPO GT4 INTEGRACIÓN ECONÓMICA DE LOS IIS

Esta encuesta está dirigida a conocer el grado de **integración económica** que existe en los IIS, y a saber cómo mejorar dicha integración. Se entiende por integración económica aquella en la que la entidad gestora del IIS **gestiona todas las ayudas económicas posibles captadas por los investigadores que provienen de las entidades integrantes del IIS y que están adscritos a dicho IIS**.

Dentro de ayudas económicas posibles se incluye todo tipo de financiación, competitiva y no competitiva: proyectos de investigación, ayudas a la contratación de personal, donaciones, mecenazgos, acuerdos con empresas, ayudas a la innovación...

Dado que existen limitaciones o especificidades impuestas por los propios financiadores, se considera como universo de proyectos posibles a gestionar dentro del IIS:
 -Aquellos en los que el IIS/entidad gestora es elegible para solicitar dichas ayudas. Así pues, no computarían las ayudas que solo pueden solicitarlas entidades como universidades, OPIS, intramurales del CIBER...
 -Aquellos en los que solicitarlos a través del IIS/entidad gestora no perjudica o condiciona las posibilidades de obtener la financiación. Así pues, no computarían las ayudas solicitadas a través de otras entidades por motivos muy concretos como cupos o límites por entidad y siempre con la autorización expresa de la dirección del IIS. Por ejemplo: ICs solicitados por el CIBER...

PREGUNTA 1: Datos generales

Nombre del IIS							
Nombre de quien completa la encuesta							
Cargo							
Email de contacto							

PREGUNTA 2: Identificación y categorización de las entidades conveniadas que forman parte de su IIS. Identificación de la entidad gestora del IIS

Por favor, complete los nombres de las entidades que conforman su IIS. Marque qué tipo de entidad es cada una. Identifique con una X cual de las entidades es la entidad gestora del IIS.

NOTA: los nombres de las entidades se rellenarán automáticamente para el resto de preguntas de esta encuesta.

		Categorización de la entidad						Entidad gestora
		Hospital	Atención Primaria	Universidad	CSC	Fundación o Centro de investigación	Otras	Marque con una X la entidad gestora del IIS
Identificación de la entidad	Entidad 1							
	Entidad 2							
	Entidad 3							
	Entidad 4							
	Entidad 5							
	Entidad 6							
	Entidad 7							
	Entidad 8							
	Entidad 9							
	Entidad 10							
	Entidad 11							
	Entidad 12							

PREGUNTA 3: Para cada una de las entidades individuales que forman parte de su IIS, ¿tienen esas entidades **otra entidad de gestión diferente** a través de la cual gestionar los proyectos?

		¿Tiene otra entidad gestora diferente?						
Identificación de la entidad	Entidad 1							
	Entidad 2							
	Entidad 3							
	Entidad 4							
	Entidad 5							
	Entidad 6							
	Entidad 7							
	Entidad 8							
	Entidad 9							
	Entidad 10							
	Entidad 11							
	Entidad 12							

PREGUNTA 4: ¿Su IIS tiene un acuerdo de integración económica total con las entidades que forman parte de dicho IIS? Es decir, si tiene un acuerdo para que todos los investigadores adscritos soliciten todas las ayudas o fuentes de ingresos posibles (según definición inicial de la encuesta) a través de la entidad gestora del IIS.

		¿Tiene acuerdo de integración económica total?	¿Tiene acuerdo de reparto de costes indirectos?	Observaciones				
Identificación de la entidad	Entidad 1							
	Entidad 2							
	Entidad 3							
	Entidad 4							
	Entidad 5							
	Entidad 6							
	Entidad 7							
	Entidad 8							
	Entidad 9							
	Entidad 10							
	Entidad 11							
	Entidad 12							

PREGUNTA 5: ¿Cómo percibe su nivel de integración económica por entidades que conforman su IIS, considerando la definición inicial?

Se considera que el nivel de integración económica es total si todas las fuentes de financiación que consiguen los investigadores pertenecientes a esa institución se gestionan a través del IIS y muy bajo si no se gestiona ninguna o casi ninguna.

		Nivel de percepción						
Identificación de la entidad	Entidad 1							
	Entidad 2							
	Entidad 3							
	Entidad 4							
	Entidad 5							
	Entidad 6							
	Entidad 7							
	Entidad 8							
	Entidad 9							
	Entidad 10							
	Entidad 11							
	Entidad 12							

PREGUNTA 6: En caso de problemas de integración, identifique por entidad si el problema concreto es por **no tener o no aplicar un acuerdo de repartición de costes indirectos** con las entidades.

		¿Existe un problema de integración por no tener reparto de CI?	Describa el problema concreto					
Identificación de la entidad	Entidad 1							
	Entidad 2							
	Entidad 3							
	Entidad 4							
	Entidad 5							
	Entidad 6							
	Entidad 7							
	Entidad 8							
	Entidad 9							
	Entidad 10							
	Entidad 11							
	Entidad 12							

PREGUNTA 7: En caso de problemas de integración, identifique por entidad si el problema es según **tipo de financiación**.

		ISCI	AEI	Otros financiadores competitivos	Sector privado (no competitivo)	Describa el problema concreto
Identificación de la entidad	Entidad 1					
	Entidad 2					
	Entidad 3					
	Entidad 4					
	Entidad 5					
	Entidad 6					
	Entidad 7					
	Entidad 8					
	Entidad 9					
	Entidad 10					
	Entidad 11					
	Entidad 12					

PREGUNTA 8: En caso de problemas de integración, identifique por entidad si existen **otros problemas de integración económica**.

		Sintetice los problemas concretos que impiden para cada entidad conseguir una integración económica total
Identificación de la entidad	Entidad 1	
	Entidad 2	
	Entidad 3	
	Entidad 4	
	Entidad 5	
	Entidad 6	
	Entidad 7	
	Entidad 8	
	Entidad 9	
	Entidad 10	
	Entidad 11	
	Entidad 12	

PREGUNTA 9: Recomendaciones de mejora para llegar a una integración económica total, concretos según entidad.

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PRIMARY CARE SURVEY

APPENDIX II: Model of the Designed Questionnaire

ISCIII Partnership Survey – Primary Care

The main objective of the IIS Partnership is to create a stable space for cooperation and joint work between the ISCIII and the accredited IIS in order to respond to the needs of the IIS, align their scientific policies with the strategic lines of the European framework, promote cooperation between the IIS creating synergies that increase their competitiveness; and promote the participation of the IIS in the definition of the ISCIII's lines of action.

This questionnaire has been developed in order to analyse the situation and identify good practices. It is initially addressed to the 11 representatives of the IIS that make up the Primary Care Working Group. Subsequently, after receiving your contributions and suggestions, it will be sent to the remaining accredited IIS and the SWOT analysis will be carried out with the 11 IIS of the group.

It is a short questionnaire that requires some quantitative information available on the IIS website, but we believe it will take you no more than 15 minutes to complete.

Thank you very much for your collaboration!

Contact Details

1. First name and surname*
2. Email *
3. Phone *

Affiliation details

4. Name of the research institute you belong to*
5. Autonomous Community

Situation analysis and good practice identification

6. Does your IIS's constituent entities explicitly include primary care (including structures that belong to single managements or have a legal entity, such as foundations)? *
Yes No
7. Do representatives of primary care form part of the board or management committee? *
Yes No
8. Are there any members of the internal scientific committee from primary care? *
Yes No
8. If yes, please specify how many *
9. Are there any members on the external scientific committee from primary care? *
Yes No

11. If yes, please specify how many *
12. Are there primary care members on other IIS committees? *
Yes No
13. If yes, please specify which ones *
14. Is any primary care researcher the coordinator or head of any Scientific Area or Programme of the IIS? *
Yes No
16. Which area or programme? *
16. How many IIS groups are led by primary care researchers? *
17. How many researchers does the IIS have and how many of them belong to primary care? *
18. How many groups are there in the IIS and how many groups do primary care researchers work in? *
19. What are the thematic areas of the groups that PC researchers belong to or lead? *
20. Are there associated clinical groups in your IIS? *
Yes No
21. Are there associated clinical groups from PA? *
Yes No
22. Is there any research support unit attached to the IIS in the primary care centre(s)? *
Yes No
23. Are there any other research support structures linked to the IIS in primary care and how many? *
24. Is your IIS attached to the SCReN platform? *
Yes No
25. Do primary care researchers participate in the SCReN platform? *
Yes No
26. Are primary care researchers present on other IIS platforms? *
Yes No
27. If yes, please specify which ones *
28. How many active, competitive, public, national or international projects have a primary care MR (approved from 2018 to present). *
29. Are there any IIS research staff contracted with HR funding obtained in national or international calls who are developing their work in primary care? *
Yes No
30. If yes, please specify how many and what type *

31. Please, indicate the number of IIS PA researchers by professional category: medicine, nursing, physiotherapy, psychology, pharmacy, other. *

Outstanding good practices in the field of primary care in your IIS

32. Please refer to some good practices promoted by the IIS in primary care *.

33. Finally, if you would like to disseminate any good practice from your IIS, please indicate the contact person so that we can gather the necessary information to highlight it in the report of the Primary Care Commission of the Partnership *

34. Please include any comments on the questionnaire and its content, or any suggestions for the future functioning of the primary care group of the IIS Partnership.

HEALTH CARE RESEARCH

APPENDIX II Survey model(s) or template(s).

- Health Research Institute to which you belong (list of 34 accredited IIS)
- Is this a specific care/nursing research group? Yes; No
- Name of the research group for which you are reporting data
- Type of group: Emerging Group; Consolidated Group; Excellent Group; Associated Clinical Group; Other
- Area of the IIS in which it is integrated
- Total number of researchers in the group
- Number of members of the research group who are nursing professionals
- Number of professionals from other professional categories
- Please, indicate which other professional categories make up the research group (select as many as necessary): Medicine, Biology, Pharmacy, Statistics, Physiotherapy, Podiatry, Psychology, Nutrition and Dietetics, Dentistry, Optics and Optometry, Veterinary and other.
- Total number of research group members employed by the university
- Number of pre-doctoral fellowships in the research group (active at the time of completion of this questionnaire)
- Number of post-doctoral fellowships in the research group (active at the time of completion of this questionnaire)
- Number of intensification fellowships (national, regional, local) in the research group (active at the time of completion of this questionnaire)
- Do any nurses belong to the Internal Committee of your IIS? Yes; No
- How many nurses are members of the internal committee of your IIS?
- Do any nurses belong to the external committee of your IIS? Yes; No
- How many nurses are members of this external committee of your IIS?
- In the last available assessment, how was the nursing research group rate?: excellent; standard; not met.
- University to which your group belongs

SUPPORT PLANS FOR THE DISSEMINATION OF SCIENCE IN NON-SCIENTIFIC AREAS: ROLE OF RESEARCHERS

APPENDIX II Survey Model. Questionnaire 1. GT6 – IIS-ISCIH Partnership. Form 1. Initial Information Gathering

1. Name of Health Research Institute (IIS)*
2. Name of the coordinator at the IIS for GT6*
3. Position of the coordinator in the IIS for GT6*
4. Email of the IIS coordinator for GT6*
5. Name of IIS Contact for GT6*
6. Position of IIS Contact for GT6*
7. Email of the IIS contact for GT6*
8. Other participants (name, position, email) in the IIS for GT6
9. Comments/suggestions on the objectives to be achieved by GT6
10. Situation in each IIS – Identification of Good Practices
(Upload the related documents to the Partnership SharePoint)*
11. Other Comments/Suggestions

Questionnaire 2. GT6 – IIS-ISCIH Partnership

Dear Friends,

From Working Group 6 (GT6) "Support plans for the dissemination of science in non-scientific areas: Role of researchers" of the IIS-ISCIH Partnership, we would be grateful if you could fill in the attached questionnaire, which shouldn't take more than 10 minutes of your time.

We would also ask you to upload the information/documentation related to the different aspects of the questionnaire to SharePoint. If you have any difficulties with this, you can also send it by email.

Thank you very much for your invaluable collaboration.

1. The Institute has a training programme for researchers in "Science Communication in Non-Scientific Fields (Scientific Dissemination)".

Yes/In development/No

If yes or in development, please describe below and provide programme(s) (upload to SharePoint or send by email)

This activity is aimed at:

- Patient and caregiver associations
- Scientific societies.
- Professional associations.
- Educational community.

- NGOs
- Media.
- Business sector
- Pharmaceutical industry.
- Neighbourhood/Civil Associations
- General public
- Not carried out

2. The Institute participates in activities aimed at society, such as Science Week, European Night, etc.

Yes /Planned/No

If yes, please describe below and provide details or programme(s) (upload to SharePoint or send by email to gestioncientifica@iisgm.es)

This activity is aimed at:

- Patient and caregiver associations
- Educational community.
- Scientific societies.
- Business sector
- Pharmaceutical industry.
- NGOs
- Media.
- Professional associations.
- Neighbourhood/Civil Associations
- General public

3. The Institute participates in activities aimed at students (primary education, Compulsory Secondary Education, baccalaureate, T&D, higher education/university), such as 4th ESO+Business (Community of Madrid) or short programmes to integrate students into research groups.

Yes /Planned/No

If yes, please describe below and provide details or programme(s) (upload to SharePoint or send by email to gestioncientifica@iisgm.es)

This activity is aimed at:

- Patient and caregiver associations
- Educational community.
- Scientific societies.
- Business sector
- Pharmaceutical industry.

- NGOs
- Media.
- Professional associations.
- Neighbourhood/Civil Associations
- General public

4. The Institute organises Conferences/Seminars aimed at the general public.

Yes /Planned/No

If yes, please describe below and provide details or programme(s) (upload to SharePoint or send by email to gestioncientifica@iisgm.es)

This activity is aimed at:

- Patient and caregiver associations
- Educational community.
- Scientific societies.
- Business sector
- Pharmaceutical industry.
- NGOs
- Media.
- Professional associations.
- Neighbourhood/Civil Associations
- General public

5. The Institute's website has specific content aimed at the general public.

Yes /Planned/No

If yes, please describe below and provide details or programme(s) (upload to SharePoint or send by email to gestioncientifica@iisgm.es)

This activity is aimed at:

- Patient and caregiver associations
- Educational community.
- Scientific societies.
- Business sector
- Pharmaceutical industry.
- NGOs
- Media.
- Professional associations.

- Neighbourhood/Civil Associations
- General public

6. The Institute produces monographs/documents/brochures, etc. with specific content aimed at the general public.

Yes /Planned/No

If yes, please describe below and provide details or programme(s) (upload to SharePoint or send by email to gestioncientifica@iisgm.es)

This activity is aimed at:

- Patient and caregiver associations
- Educational community.
- Scientific societies.
- Business sector
- Pharmaceutical industry.
- NGOs
- Media.
- Professional associations.
- Neighbourhood/Civil Associations
- General public

7. The Institute has a communication strategy with specific content aimed at the general public.

Yes, but not particularly structured

Yes, it has a Communication Unit

Yes, it is deployed by the Hospital's Communication Service.

Other

No

If yes, please describe below and provide details or programme(s) (upload to SharePoint or send by email to gestioncientifica@iisgm.es)

This activity is aimed at:

- Patient and caregiver associations
- Educational community.
- Scientific societies.
- Business sector
- Pharmaceutical industry.
- NGOs

- Media.
- Professional associations.
- Neighbourhood/Civil Associations
- General public

8. The Communication Strategy includes presence in:

- Press
- Television
- Twitter
- Youtube
- LinkedIn
- FaceBook
- Instagram
- Other (information screens in the hospital or other centres of the Institute, etc.).

9. The Institute has a specific training programme for “non-scientific actors” who participate in governing bodies, advisory bodies, committees, etc.

Yes/In development/No

If yes or in development, please describe below and provide programme(s) (upload to SharePoint or send by email)

This activity is aimed at:

- Patient and caregiver associations
- Educational community.
- Scientific societies.
- Business sector
- Pharmaceutical industry.
- NGOs
- Media.
- Professional associations.
- Neighbourhood/Civil Associations
- General public

10. The institute has tools to assess the satisfaction of the target audience of the activities.

Yes/In development/No

If yes or in development, please describe below and provide programme(s) (upload to SharePoint or send by email)

APPENDIX III. Bibliography

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- PGDOnline: <https://pgd.consorciomadrono.es/>
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PARTICIPATION OF NON-SCIENTIFIC KEY ACTORS IN IIS ACTIVITIES

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APPENDIX IV. Additional Documents

IIS RESEARCHERS' CAREERS

- Decree 17/2019, of 15 March, approving the Statute of non-established Research Workers at the Service of the Health Research Institutes of the Balearic Islands. GOVERNING COUNCIL. Published in BOIB no. 35 of 16 March 2019. In force from 17 March 2019. Revision in force from 01 January 2023. (<http://www.caib.es/eboibfront/es/2019/10956/619724/decreto-17-2019-de-15-de-marzo-por-el-que-se-aprue>)
- Law 15/1997, of 25 April, authorising new forms of management of the National Health System. <https://www.boe.es/eli/es/l/1997/04/25/15/con>
- Law 14/2011, of 1 June, on Science, Technology and Innovation. <https://www.boe.es/eli/es/l/2011/06/01/14/con>
- Law 53/1984, of 26 December, on incompatibilities of staff in the service of public administrations. <https://www.boe.es/eli/es/l/1984/12/26/53/con>
- Law 3/2017, of 27 June, on the General State Budget for 2017. <https://www.boe.es/eli/es/l/2017/06/27/3/con>
- Law 53/1984, of 26 December, on incompatibilities of staff in the service of public administrations. <https://www.boe.es/eli/es/l/1984/12/26/53/con>
- Law 3/2017, of 27 June, on the General State Budget for 2017. <https://www.boe.es/eli/es/l/2017/06/27/3/con>

DATA MANAGEMENT PLAN

- Digital Curation Centre (DCC) Template: Checklist for a Data Management Plan, v.4.0. Edinburgh: Digital Curation Centre. Available at: <http://www.dcc.ac.uk/resources/data-management-plans>
- Data Science Journal: 10.5334/dsj-2019-059. Reference associated with DSW: Data Stewardship Wizard.
- DMP Online: <https://www.dcc.ac.uk/resources/data-management-plans>
- DSW: Data Stewardship Wizard: <https://ds-wizard.org/>
- EasyDMP: <https://easydmp.sigma2.no>
- EINA.DMP (CORA): Repository mentioned in the document
- PGDOnline: <https://pgd.consorciomadrono.es/>
- Argos: <https://argos.openaire.eu/> y <https://argos.openaire.eu/open-source-licences>
- Participation of non-scientific key actors in IIS activities

MONITORING SYSTEM FOR MONITORING THE INVOLVEMENT OF NON-SCIENTIFIC KEY ACTORS IN THE IIS:

DIMENSION	Objective	Actions	Indicators
		To include the participation of non-scientific key actors in the mission of the Institute.	Participation of non-scientific key actors is included in the mission of the Institute.
	To involve non-scientific key actors in the planning and definition of strategies, organisation and management of the IIS through their inclusion in internal bodies and/or committees of the Institute and through agreements with external organisations led by or with the participation of non-scientific key actors.	To involve non-scientific key actors in the development and/or review of the Institute's strategies, policies and/or action plans.	Number of strategies, policies and/or action plans in which non-scientific key actors have been involved. (Participation in prioritisation of research lines, joint science project, strategic plan, dissemination plan, training plan or resource raising).
		To include representatives of non-scientific key actors in the Institute's governing bodies, commissions and/or evaluation committees.	Number of representatives of non-scientific key actors (associations, patients, carers, community, etc.) included in the institute's governance bodies.
GOVERNANCE		To encourage and support the establishment and maintenance of institutional and cooperation agreements with external organisations led by or involving non-scientific key actors (e.g. associations, NGOs, companies...).	Number of representatives of non-scientific key actors (associations, patients, carers, community, etc.) on the institute's commissions or committees.
		To encourage the diversity of non-scientific key actors involved in the IIS.	Number of internal calls for proposals (e.g. intramural projects, awards, etc.) involving non-scientific key actors in the evaluation committee. Number of institutional cooperation agreements of the IIS with associations, communities, etc. Number of agreements between the institution and companies.

DIMENSION	Objective	Actions	Indicators
		<p>To establish and/or maintain a budget (€€€) and appoint qualified staff dedicated to non-scientific key actors involvement in the activities of the institute.</p>	<p>Institute's budget dedicated to the participation of non-scientific key actors.</p>
		<p>To facilitate and encourage applications for funding in calls for proposals initiated by non-scientific key actors organisations or associations (NGOs, patient associations...) by disseminating information on relevant calls for proposals and/or by providing effective support in the application process.</p>	<p>Number of staff dedicated to managing non-scientific key actors involvement as a specific part of their work.</p>
	<p>To obtain and/or maintain financial or human resources dedicated to the engagement activities of non-scientific key actors or resources obtained from the actors for research purposes.</p>	<p>To include elements of non-scientific key actors participation as an evaluation criterion in the Institute's internal calls for proposals (intramural projects, awards, recognition, etc.).</p>	<p>Funding obtained from calls for proposals launched by non-scientific key actors associations or bodies (NGOs, patients' associations, etc.).</p>
<p>RESOURCES AND PROJECTS</p>	<p>To involve non-scientific key actors in the research process.</p>	<p>Coordination with related hospitals and universities to share actions for the participation of non-scientific key actors.</p>	<p>Funding requested from calls for proposals launched by non-scientific key actors associations or bodies (NGOs, patients' associations, etc.).</p>
			<p>Number/percentage of projects in which an association, NGO, etc. was involved in the planning phase of the research.</p>
		<p>To encourage the participation of non-scientific key actors in the design, development and execution of research projects.</p>	<p>Number/percentage of projects in which an association, NGO, etc. was involved in the implementation phase of the research.</p> <p>Number of internal calls for proposals (e.g. intramural projects, awards, mobility, etc.) which include elements of non-scientific key actors involvement as an evaluation criterion.</p>

DIMENSION	Objective	Actions	Indicators
TRAINING:	To carry out activities aimed at facilitating the training and upgrading of skills for both non-scientific key actors and research staff to carry out research participation activities.	To organise training activities for different non-scientific actors (patients, decision-makers, etc.).	Number of training activities targeted at different non-scientific actors in the system (patients, decision-makers, etc.).
	To disseminate information on external activities aimed at researchers on the involvement of non-scientific key actors in the different phases of research.	To organise training activities for researchers and/or managers on the involvement of non-scientific key actors in the different phases of research.	Number of training activities aimed at participation and/or co-design activities of non-scientific key actors in the research planning phase (research design and/or implementation).
DISSEMINATION:	To consider and involve non-scientific key actors in the translation of research through various dissemination and communication activities aimed at or delivered by non-scientific key actors.	To disseminate information on external activities aimed at researchers on the involvement of non-scientific key actors in the different phases of research.	Number of training activities on science communication aimed at researchers*.
	To promote and encourage the training and participation of researchers in external organisations	To disseminate information on external activities aimed at researchers on the involvement of non-scientific key actors in the different phases of research.	Number of training activities on science communication aimed at researchers*.
DISSEMINATION:	To consider and involve non-scientific key actors in the translation of research through various dissemination and communication activities aimed at or delivered by non-scientific key actors.	To disseminate information on external activities aimed at researchers on the involvement of non-scientific key actors in the different phases of research.	Number of training activities on science communication aimed at researchers*.
	To consider and involve non-scientific key actors in the translation of research through various dissemination and communication activities aimed at or delivered by non-scientific key actors.	To disseminate information on external activities aimed at researchers on the involvement of non-scientific key actors in the different phases of research.	Number of training activities on science communication aimed at researchers*.

DIMENSION	Objective	Actions	Indicators
		To participate in and/or organise regular knowledge exchange activities between researchers and non-scientific key actors (invited talks by non-scientific key actors, visits to associations, NGOs, etc.).	Number of open days organised by the institute.
	To consider and involve non-scientific key actors in the translation of research through various dissemination and communication activities aimed at or delivered by non-scientific key actors.	To designate persons responsible for communication with the public and provide their contact information on the institute's website and/or other communication channels.	Number of public lectures organised by the institute, involving and/or empowering different non-scientific key actors. Number of press releases on research results. The institute has designated staff as public contact persons (e.g. with details on the website). Examples of good practice of non-scientific key actors engagement are regularly updated on the institute's website.
DISSEMINATION:		To include and regularly update on the Institute's website and/or disseminate on its social media good practice examples of non-scientific key actors engagement.	Number of lectures, presentations, participations, etc. by guests of external organisations (associations, NGOs, companies, etc.).
	The involvement of non-scientific key actors in the production of research outputs such as publications, tools and/or other products.	To encourage co-production with non-scientific key actors through various measures, such as including it as an evaluation criterion for awards or as a recommended activity for research groups.	Number of visits to external organisations (associations, NGOs, companies, etc.).
PRIMARY OUTCOMES	To identify the portfolio of research products and results of potential interest to institutions and companies.		Number of scientific publications in collaboration with external non-scientific organisations (industry, NGOs, patients, civil society, etc.) in which non-scientific actors are signed as authors or mentioned in the acknowledgements. Publications, materials and/or tools aimed at different non-scientific key actors.

DIMENSION	Objective	Actions	Indicators
	To motivate and encourage research staff to involve non-scientific key actors at different levels of participation. To regularly assess the satisfaction of non-scientific key actors' expectations following their participation in public participation processes and identify actions for improvement.	To establish and/or maintain incentives for researchers or mechanisms for official recognition of participation in public participation processes (e.g. including awards or other recognition as a criterion for assessing the activities of research groups). To establish and maintain a system for assessing the satisfaction of non-scientific key actors, such as an annual survey, contact form, suggestion box, etc.	The institute has incentives for researchers or mechanisms for official recognition of participation in public participation processes.
Motivation and satisfaction		To feed back non-scientific key actors satisfaction to the research staff involved, suggesting improvements to the process where appropriate (e.g. process to be carried out by staff dedicated to non-scientific key actors engagement as a specific part of their work).	The institute has an annual system for assessing and improving the satisfaction of non-scientific key actors.

INVOLVEMENT OF NON-SCIENTIFIC KEY ACTORS IN IIS ACTIVITIES

APPENDIX V (of the document) Detailed review of the technical guide for the evaluation and accreditation of the IIS

CRITERION	CONTENT OF THE CRITERION	RRI PRINCIPLES INVOLVED
1.2.1.2	The composition of the IIS governing bodies is proportionate to the capacities and entities that make up the IIS. The principles of gender equality shall be taken into account in the appointment of members, except for those bodies whose composition is determined by the position held.	Gender equality and governance
1.2.3.2	The rules of procedure of the ESC establishes that: – It is a body with independence of criteria and autonomy of decision in the performance of its functions in relation to the IIS. – Minutes must be taken of all its meetings, whether in person or by telematic means. – Its composition respects the principles of gender equality.	Ethics, gender equality and governance.
1.2.3.3	The rules of procedure of the ESC establishes that its members must prove that they have no conflict of interest.	Ethics and governance
1.2.7.1	There is an Internal Scientific Committee (ISC), chaired by the Scientific Director of the IIS, whose rules of procedure state that it is composed of researchers, including researchers in training, representing the priority scientific areas of the IIS. The different types of researchers must be represented and the principles of gender equality must be respected. It must include those responsible for training, innovation and quality at the IIS, as defined in the IIS organisation.	Gender equality, governance and science education
1.3.1.2	Channels and pathways are operational and effective for internal transparency, communication of necessary and useful information to researchers and other staff of the IIS, and their active participation in the IIS. They meet the communication and participation objectives.	Ethics and governance
1.3.1.3	There is a website that complies with the requirements of Law 19/2013, of 9 December, on Transparency, Access to Public Information and Good Governance.	Ethics and governance

CRITERION	CONTENT OF THE CRITERION	RRI PRINCIPLES INVOLVED
1.3.1.4	<p>There is a website that provides at least the following information: Institutions that make up the IIS and governing bodies; Organigram of the IIS; Physical centres that make up the IIS; List of scientific areas/scientific programmes with the groups included in each area; Summarised CV names of: Scientific Director, Heads of each Scientific Area and of each Research Group; Contact details of: Scientific Director; management area; scientific areas and research groups; summary of its strategic plan; scientific report for at least the last two years; portfolio of products of potential interest to the productive sector. Clinical practice guidelines (GPC) prepared with the participation of IIS researchers; Mechanisms for citizen participation. · Employment and recruitment opportunities. · A summary of the financial report for at least the last two financial years. · In accredited IIS, the website informs of this accreditation and displays the ISCIII logo.</p>	Governance and citizen participation
2.1.1.2	<p>The SP contains at least the following three strategic objectives:</p> <hr/> <p>– Translational research. This strategic objective aims to ensure that the IIS is a translational research organisation that generates knowledge that has an impact on the NHS.</p> <hr/> <p>– Innovation. This strategic objective is focused on products, processes and organisational practices that are useful to the healthcare organisation.</p> <hr/> <p>– International positioning. This objective aims to:</p> <hr/> <ul style="list-style-type: none"> • the generation of internationally recognised knowledge <hr/> • the positioning in processes to attract internationally competitive resources for research and innovation. 	Governance
2.1.3.1	<p>The IIS has a plan that develops the IIS quality policy, approved by the governing body and not more than 5 years old. The plan defines: objectives, methodology, channels for staff participation, indicators, timetable and responsibilities.</p>	Governance
2.1.3.2	<p>The quality policy is disseminated and known by the IIS staff. The usefulness of the channels of participation in the activities of the IIS Quality Committee is verified.</p>	Governance

CRITERION	CONTENT OF THE CRITERION	RRI PRINCIPLES INVOLVED
2.2.2.1	The IIS has a human resources plan for research, technical and management staff. This plan includes at least specific actions on: <hr/> – Research careers. <hr/> – Generational change-over <hr/> – Female leadership.	Ethics, gender equality and governance.
2.2.2.2	The human resources plan includes measures for recruitment, professional development and research talent, with explicit reference to the integration of clinical groups and the development of emerging groups.	Ethics and governance
2.2.2.3	The human resources plan includes gender equality and diversity management actions addressing: equal opportunities and equity aspects in research careers; considerations in the recruitment policy for research, technical, management and other services staff; aspects of representation in the different bodies and committees.	Ethics, gender equality and governance.
2.2.2.4	The human resources plan defines a policy for “Open, transparent and merit-based recruitment of researchers”.	Ethics
2.2.2.5	The IIS internally informs about the EURAXESS web services and advertises its job vacancies for researchers, managers and technicians on EURAXESS Jobs.	Governance
2.2.2.6	The IIS adheres to the European Charter for Researchers and the Code of Conduct for the Recruitment of Researchers (C&C).	Ethics and governance
2.2.2.7	The IIS has a plan for compliance and implementation of the principles defined in the C&C, approved by the governing bodies.	Ethics and governance
2.2.2.8	The IIS assesses the human resources plan and the gender equality and diversity management plan every 2 years using the methodology set out in the plan.	Ethics, gender equality and governance.
2.2.2.9	Necessary improvement actions have been implemented according to the evaluation of the human resources plan.	Governance

CRITERION	CONTENT OF THE CRITERION	RRI PRINCIPLES INVOLVED
2.3.7.1	The IIS has established and is developing a defined Open Science policy that includes: <ul style="list-style-type: none"> · The mandate and incentives to promote open access to publications, in open access media and in recognised, standardised repositories compatible with European infrastructures (e.g. OpenAire). · Facilitating the open publication of data in repositories standardised and recognised in the discipline. The European open data infrastructure EOSC (European Open Science Cloud) is used as a reference. 	Open Access
2.3.7.2	At least 25% of the publications resulting from publicly funded projects during the assessment period have been published in Open Access media.	Open Access
2.3.7.3	In the last year, at least 50% of the research data resulting from publicly-funded projects have been made openly available in standardised and discipline-recognised open data repositories in accordance with the FAIR (Findable, Accessible, Interoperable and Reusable) principles.	Open Access
2.3.7.4	The IIS provides support and advice to researchers on obligations, Open Access publishing options, copyright or Creative Commons licences, etc.	Open Access and Governance
2.3.7.5	IIS provides support for the creation of research data management plans (DMPs).	Governance
3.1.1.1	There is a plan for the translation of scientific results from the IIS into clinical practice and the productive sector, both within the IIS and globally. This strategy includes actions for the participation of key actors.	Governance and citizen participation
3.1.1.2	The actions foreseen in the translation plan have been implemented.	Governance
3.1.1.3	The health innovation objective of the SP is monitored and evaluated, including the objectives related to product, service and process innovation in clinical care and health services.	Governance
3.1.1.4	In the last 2 years, at least four actions have been carried out among researchers to promote at least: a) an increase in registered and licensed patents b) the transfer of knowledge to the productive sector c) the development of new health products or marketable devices d) the implementation of new clinical processes e) the creation of spin-offs and start-ups f) Clinical trials or academic studies.	Science education
3.1.2.1	The number of guidelines published in indexed journals in the last 5 years, plus the number of institutional publications in which the IIS has participated is ≥ 10	Open Access

CRITERION	CONTENT OF THE CRITERION	RRI PRINCIPLES INVOLVED
3.1.2.2	Guidelines produced as a result of IIS research activities are collected in the IIS information system and disseminated both on the IIS website and actively to IIS hospital and primary care services.	Governance and Open Access
3.1.2.3	Evidence of implementation is presented with impact analysis in terms of process and/or health outcome indicators.	Open Access
3.1.2.4	In the last 5 years, at least 5 or more results of research conducted at the IIS have been translated into health care practice, at least in the health centres that make up the IIS.	Governance
3.1.2.5	The IIS has identified research results of potential interest for health care activities. At least 2 actions have been carried out in the last 12 months to disseminate these results to healthcare institutions and professionals, at least in the IIS environment. Portfolio of products of interest to clinical practice.	Open Access
3.1.3.2	At least one action per year in the last two years to disseminate the portfolio of products and research results of potential interest to potentially interested institutions and companies has been organised.	Open Access and science education
3.2.1.1	Training activities on science communication for non-scientific key actors have been organised at least once in the last year.	Citizen participation Science education
3.2.1.2	Training activities on mechanisms for translation into practice have been organised at least once in the last year.	Science education
3.2.1.3	Training activities on participation and co-creation in scientific research, or other ways of opening up participation in research to non-scientific key actors have been carried out at least once in the last two years.	Citizen participation Science education
3.2.2.1	A scientific communication plan is in place, both externally to the IIS and internally to create synergies between research lines.	Governance, Citizen participation and Science education
3.2.2.2	The communication plan aligns the objectives of the SP and the plan for translation and impact on society.	Governance and science education
3.2.2.3	External science communication includes at least 2 actions per year to: 1. Give visibility to the IIS; 2. Reinforce the objectives of the SP; 3. Support the plan for translation and impact on society and the NHS.	Governance and science education

CRITERION	CONTENT OF THE CRITERION	RRI PRINCIPLES INVOLVED
3.2.2.4	Internal scientific communication includes at least the following actions: dissemination of knowledge in the IIS and in the hospital and PC environment, and identification and promotion of synergies between lines of research.	Governance and science education
3.2.2.5	The number of dissemination activities to the general public has increased over the last 5 years. It reaches a number of 5 actions per year at the time of application for accreditation.	Science education
3.2.2.6	The IIS actively participates in the scientific dissemination activities organised by the ISCIII together with other IIS.	Science education
3.2.3.1	The IIS has involved non-scientific key actors at some phase in the development of the strategic plan.	Citizen participation
3.2.3.2	The IIS has involved non-scientific key actors in the prioritisation of research lines.	Citizen participation
3.2.3.3	The IIS has involved non-scientific key actors in fundraising.	Citizen participation
3.2.3.4	Non-scientific key actors participate in governance bodies.	Governance and science education
3.2.3.5	Research projects in the last 2 years have involved non-scientific key actors in the design and development of the research.	Citizen participation
3.2.3.6	The satisfaction of non-scientific key actors who have participated in the research activity at its different stages is assessed at least annually.	Citizen participation

SUPPORT PLANS FOR THE DISSEMINATION OF SCIENCE IN NON-SCIENTIFIC AREAS: ROLE OF RESEARCHERS

Download from WeTransfer: <https://we.tl/t-ol5gJfdfQn>

1. In more than half of the IIS, the PC appears as a constituent entity or there are ascription agreements for the PC structures in several IIS.
2. Most IIS have PC researchers as members of the internal scientific committee.
3. In half of the IIS, the percentage of groups with PC collaborators exceeds 10%.
4. The majority of IIS have an associated clinical group.
5. The average number of projects with PC IP is 4.0.
6. Diversity of research lines led by PC.
7. PC generates essential clinical databases for RWD research.
8. Telematic solutions for meetings and group work reduce the disadvantages of the dispersion of PC.

