How to listen to, gather & act on your community's needs and insights

Your project planner

What is this tool and what is it for?

This is a project planner. It has been designed to help **rare disease patient organisations** and **patient representatives** plan, organise, and keep track of the decisions made during the design, development and dissemination of your data collection project.

How is this tool organised and how should I use it?

It is organised into **10 different Steps**:

For each Step you will find different questions to guide and support your project planning process. Additionally, you can use this tool as a methodology tracker which can be very useful if you decide to publish your results.

Before embarking on any project that requires collecting data from your community, keep in mind that **funding** and **legal and ethical compliance** are 2 factors that can have a substantial impact in the viability of your project.

1. Funding

Having funding can make the difference between a green light (i.e., you are ready to launch to your project) and a red light (i.e., you need first to develop a funding strategy and secure initial funding). Answering the 3 following questions will help you map and clarify your funding needs.

1. Have you secured any funding?

- ☐ Yes
- ☐ No, because I don't need it
- ☐ No, but I'm looking for funding opportunities
- ☐ I don't know

2. Are you anticipating having any expenses?

- ☐ Yes
- ☐ No
- ☐ I don't know

3. If you answered yes to question 2, in which of the following tasks are you anticipating/planning to spend money on: (Select all that apply)

- ☐ Participant recruitment
- ☐ Data collection (paying for a platform, software, outsourcing, etc)
- ☐ Data analysis (paying for a platform, software, outsourcing, etc)
- ☐ Result dissemination
- ☐ Hire expert consultants (e.g., for ethical/legal advice, data analysis)
- ☐ Other (please specify):

You may use the budget planner below as a basis to plan your funding strategy. **Tip –** *revisit this table regularly while you are developing your project approach and amend as needed:*

Task	How much will you need?	Who will carry out the task	Have you secured funding for this?	
			Yes	No

2. Legal and ethical compliance

Legal and ethical compliance are extremely relevant in any project collecting personal data, especially if it is health data. It is important for you to carefully plan and consider how to respect and follow the most up-to-date Codes of Conduct and observe the legal obligations established by the General Data Protection Regulation (GDPR) and relevant national data protection legislation.

Do you need to get your project approved by an ethics committee? This will depend on the country, the project and how you reach out to respondents (e.g., online, through a hospital...) and/or if you are planning to publish your findings in a scientific journal.

Unless you have in-house expertise on these matters, our recommendation is to **get advice and support from experts in this field**.

Now that we have looked into funding and legal/ethical compliance, it is time to start our step-by-step journey.

Let the project planning begin!

STEP 1. Define the topic of your project

"**What do I want to explore?**"

This is the first step when conducting any project that involves health data collection and analysis. What you decide now will determine the focus of your project. No pressure! Instead, dedicate time to reflect and debate with your team options and possibilities.

Find time to brainstorm: This is the time to ask yourself and others what is the topic you will focus on. Think about:

- what is a priority for your community?
- are there any important evidence gaps?
- what is coming on the horizon?
- If there are competing priorities, what criteria will you use to prioritise (feasibility, timeliness, urgency, long-term or short-term impact, ...)
- ...

You may want to put some ideas down!

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Priority list
1. 2. 3. 4. 5.
Final decision:
Reason(s) for choosing this topic:

STEP 2. Define Your Objectives

"What do I want to find out?"

Narrow down and define what is the specific purpose and intent of your project. Transforming it into a question can help you to further develop it. What are you trying to find out?

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Well done! You may now want to establish the concrete actions that will allow you to reach your objective(s). To guide you through this process, you may use the table below:

Objective	**Tasks per objective** (Be as specific as possible)	**Resources needed per task** (if you do not have the expertise in house, note it down)	**Timeline** (estimate how much time you will need to perform the task)	**Person in charge** of the task	**Done?**

STEP 3. Assemble Your Team

"**Who needs to be involved?**"

Now it is time to put a winning team together, people that have the expertise you need.
Can you do it with your in-house resources or do you need to reach out to external partners?

To help you keep track of your team assembly process, fill out the table below:

Name	Contact	Expertise	Invited?	Accepted?

STEP 4. Do Background Research

"Where are you starting from?"

It is now time for you and your team to do some background research.
This is so important and can be extremely valuable to you as it can:

- save time
- help to refine your objectives
- identify tools and data that you can incorporate into your project
- avoid duplication
- identify results that you can compare your own results with.

To guide you through this step, you may fill the table below. We promise it will be worth it!

Data sources searched (e.g., journals, ERN website, professional expert advice)	**Did you find any useful information?**	**If yes, what was it?** (Add hyperlink if available online)	**If yes, how are you going to use it?**

STEP 5. Define Your Target Audience and Set Your Recruitment Strategy

"**Who do you need to hear from?**" and "**How do you recruit them?**"

It's time to identify who your target audience is (i.e., from whom you want to gather information). Closely linked to this is outlining an efficient recruitment strategy to ensure that you get a good number of responses.

Our target audience is (be specific! add age, gender, disease, etc):

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To help you decide which channel or combination of channels you should use in your recruitment campaign, think through, and answer the following questions:

1.Do you know your target audience? ☐ Yes ☐ No ☐ Other (please specify):	
2.Have you reached out or worked with them before? ☐ Yes ☐ No ☐ Not applicable	- If you have reached out to them before and it has worked well, then you should probably replicate that strategy. - If you have reached to them before and it didn't go well, reflect, and analyse why that happened. After that, outline a new approach. - If you haven't reached out to them before, introduce yourself. Talk to them and explain the project to them. Consider asking for their input.
3.Do you have their contact information? (Select all that apply) ☐ Yes, email ☐ Yes, telephone number ☐ Yes, other (please specify): ☐ No ☐ I don't know ☐ Not applicable/needed	- If the answer is yes, then you have a great asset. Use it well! - If you don't have this information, gathering this data needs to be your top priority.

4.Are they tech-savvy? ☐ Yes ☐ No ☐ I don't know	- If the answer is yes, you should probably opt for virtual and online platforms, such as emailing and/or social media. - If the answer is no, then choose other channels, like letters, phone calls, face to face meetings. - If you don't know, you need to find out!
5.Do they use social media? ☐ Yes ☐ No ☐ I don't know	- If the answer is yes, you should carefully consider using it as a channel in your recruitment strategy. Plan accordingly. You will need to develop posts, visual aids and maybe even videos. - If they don't, then drop it. No social media posts. - If you don't know, you need to find out!
6.Which social media platforms do they prefer? (Select all that apply) ☐ Facebook ☐ Twitter ☐ Instagram ☐ WhatsApp ☐ LinkedIn ☐ Other (please specify): ☐ I don't know ☐ They don't use social media	- If they use one or more social media platforms, don't forget to adapt your posts to the social media platforms in question. - If they don't, then drop it. No social media posts. - If you don't know, you need to find out!

Final decisions:

Now that you have analysed where your target population is, it is time to make a final decision.

7.Which channels are you going to use in your recruitment strategy?

8.When do you plan to start the recruitment? How long do you think the recruitment process will take?

9.Who can help you maximise the recruitment?

STEP 6. Select Your Data Collection Method

"Which approaches are the most appropriate to capture the voice (insights) of your community on the topic you want to explore?"

You have reached the point where you need to choose and work on your data collection methodology and tool. Before you reflect and answer the questions below, read this **Summary Table of Methods** to know more about each method and tool, and get some concrete tips and advice.

1.To decide which method to use, choose what you want to know: ☐ **A. How many** people experience or think something, or **how often** something happens? ☐ **B. How** or **why** people do or think something? ☐ **C.** A combination of **both** ☐ **D.** I don't know	- If A, you should use **quantitative methods**. - If B, you should use **qualitative methods**. - If C, you should consider a **mixed methods approach.** - If D (you don't know), you need to fully investigate and clarify this with your team. You can also know more about each method and get some concrete tips and advice in this **Summary Table.**

If you are planning to use **quantitative methods** (to answer to questions such as "how many" or "how often")

2.Do you have access to existing data with the information you need (previous surveys, health data, government data...) ☐ Yes ☐ No ☐ I don't know	- If yes, you can plan a **secondary data analysis**: you will have quantitative data without having to survey your community. - If no, you will have to survey your community. - If you don't know, you need to fully investigate and clarify this. Do your Background research (**Step 4**)
3.Do you want to ask questions to your community? ☐ Yes ☐ No ☐ I don't know	- If yes, you will need to develop a **questionnaire** with your team. You may want to browse the Rare Barometer Question repository to get some inspiration to develop your questionnaire. - If no, you should try and get access to existing data. - If you don't know, you need to fully investigate and clarify this.

If you are planning to use **qualitative methods** (to answer to questions such as "how" or "why"):

4.To answer your questions, is it better for you to directly ask people what they think or what they do? ☐ Yes ☐ No ☐ I don't know	- If the answer yes, then you can choose to have **one to one interviews** with each respondent, or to organise **focus groups**. - If no, please answer the following question. - If you don't know, you need to fully investigate and clarify this. Consulting your team is probably a good option.
5.Do you want to observe directly what people do or say in specific situations (e.g., group meetings, care)? ☐ Yes ☐ No ☐ I don't know	- If yes, you should proceed with **direct observations**: make sure that you have access to the places and people you want to observe. - If no, please answer the following question. - If you don't know, you need to fully investigate and clarify this. Consulting your team is probably a good option.
6.Do you need to use the information included in some documents? ☐ Yes ☐ No ☐ I don't know	- If yes, you can **analyse archives to gather data**: make sure that you have access to all the documents you need. - If no, you should use another qualitative data collection method. - If you don't know, you need to fully investigate and clarify this. Consulting your team is probably a good option.

To help you feel more confident with your data collection strategy, think through, and answer the following questions:

7.Are you sure that your data collection method and tool will allow you to respond to the question that you are trying to answer with this project? ☐ Yes ☐ No ☐ I don't know	- If yes, then you are probably on the right track! - If the answer is no, then you should consider other data collection approaches. - If you don't know, you need to investigate and clarify this. Consulting with your team or seeking external advice from a social researcher is probably a good option.
8.Are you sure your target audience will feel comfortable with the data collection tool you've chosen? ☐ Yes ☐ No ☐ I don't know	- If the answer yes, then this is likely to be a very good option! - If the answer is no, then you should consider other data collection approaches. - If you don't know, you need to fully investigate and clarify this. Consulting with your team is probably a good option.

9.Does your target audience have any issues that you should consider before selecting your data collection tool? ☐ Yes (e.g., vision or intellectual impairment) ☐ No ☐ I don't know	- If the answer is yes, then you should carefully analyse them and think of adaptations needed to make sure they are able to participate! - If the answer is no, then go ahead as planned. - If you don't know, you need to fully investigate and clarify this. Consulting with your team is probably a good option.

Final decisions:

Now that you have reflected on your data collection strategy and tool(s), it is time to make a final decision.

10.We are planning to collect (select all that apply)**:**

☐ Questionnaires:
- Online
- Face to face
- By phone
- Self-administered
- Filled in by investigators

☐ One-on-one interviews:
- Online
- Face to face
- By phone

☐ Focus groups
- Online
- Face to face

☐ On-site direct observations

☐ Archives

☐ Other (please specify): ____

Comments/notes:

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Now that you have picked your data collection tool, you may want to browse the [Rare Barometer Question repository] to get some inspiration for your survey.

STEP 7. Organise your data collection

Now that you have chosen your data collection method(s), you should make sure that you have all the resources you need.

1.Did you finish to write, translate, and test your data collection tool(s) (e.g., questionnaire, interview guide, focus group guide, observation guide, archive analysis framework)**?** ☐ Yes ☐ No	- If yes, you are probably on the right track! - If no, you need to take some time to do it: the quality of your data collection will depend on it! You can find some concrete tips and advice in the **Summary Table** .
2.Do you have all the resources (e.g., funding, people, supplies, software) **you need for your data collection?** ☐ Yes ☐ No ☐ I don't know	- If yes, you are probably on the right track! - If no, you should consider increasing your resources (e.g., getting more funds, involving more people, finding the right software) or adapting your data collection methods. - If you don't know, please carefully consider each step of your data collection and the resources needed. Consulting with your team is probably a good option.
3.Do you plan to monitor responses regularly (i.e., check the number of respondents, response rate, completion rate)**?** ☐ Yes ☐ No ☐ I don't know	- If yes, you are probably on the right track! - If no, you should consider a way to monitor responses, this will help you adapt your data collection and participant recruitment strategies accordingly. - If you don't know, you need to fully investigate and clarify this. Consulting with your team is probably a good option.
4.Did you organise your data management (gathering all your data in the same place: e.g., filled questionnaires, recordings and transcripts of interviews and focus groups, all your notes)**?** ☐ Yes ☐ No ☐ I don't know	- If yes, you are probably on the right track! - If no, you should consider a way to manage your data: it is important to keep track and to organise all the data you collect! - If you don't know, you need to fully investigate and clarify this. Consulting with your team is probably a good option.

Comments/notes:

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STEP 8. Analyse and Interpret Your Data

At this point, it is all about devising a good, solid plan to properly analyse and interpret the data that you have collected.

To do this, you may want to define:

How (type of analysis, software to be used -check some suggestions here)	**Who is doing it**	**When** (set a deadline)

After analysing your data, you need to interpret it. **To help you better understand and frame your results:**

- Discuss them with your team
- Put your results into context (i.e., frame them within your research aim or target audience).
- Check if any published information can help you make better sense and frame your results.

Other ideas:

STEP 9. Disseminate Your Findings

You are almost ready! But there are some very important steps left for you to take.
It is time to plan how you are going to give back to the community and decide how, when and with whom you are going to share your results.

1.When are you planning to share your findings? (Select all that apply) ☐ We will be sharing periodic updates and intermediate results ☐ We will only share the final results ☐ I don't know	- Sharing periodic updates is the best option to generate trust, increase access to and visibility of your work. If you are sharing periodic updates, you must properly plan how, who and when you are going to do it! - Only sharing final results is often the less complicated option, but that doesn't mean it is the best one. Think it through. - If you don't know, you need to make a decision on this. Brainstorm with your team.

It is critical to think **about whom you want to share your findings with**. Make sure to share them with all who have helped you, might be interested in/benefit from having access to them and/or to those who can help you put them into action.

2.With whom are you planning to share your findings? (Select all options that apply)

☐ My patient community
☐ Healthcare professionals
☐ Research community
☐ Students (e.g., medical students)
☐ Decision-makers (e.g., policymakers, regulators, politicians)
☐ Other (please specify): ________________________________

3.Why are you sharing your results with them? (Include here why is important to share with each of the stakeholders you've selected)

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4.How are you planning to disseminate your results? (Select all options that apply)

Communication channels	Communication formats
☐ Email ☐ Newsletters ☐ Webinars/meetings/ Conferences ☐ Media (e.g., magazines, TV) ☐ Social media and other online channels (websites, dashboards, online survey platforms)	☐ Project Summary Reports ☐ Video ☐ Audio (e.g., podcast) ☐ Infographics/posters ☐ Presentations (e.g., PPT) ☐ Scientific papers ☐ Factsheets

-> Remember to **adapt the communication channels** and **formats** to you target audiences.

5.Are you planning to make your results and other outputs (e.g., survey template, images, raw data) freely available? ☐ Yes ☐ No ☐ I don't know	- Sharing outputs can help others and avoid duplication. If yes, think about how you will do it (where they will be accessible and in what format). - If the answer is no, then clearly identify what is preventing you to share. - If you don't know, you need to reflect about this aspect and take a decision.

6.Why? (Please justify your choice)

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7.How are you going to make your results accessible? (Select all options that apply)

☐ Sharing the raw data/results

☐ I don't plan on making my data and other outputs and materials available. I will only share my analysis and interpretation of the results

☐ Other (please specify): ____

STEP 10. Systematise the Lessons Learnt

It is now time to tell reflect on what you've achieved, but also on the process itself.

First, let's reflect on participation:

1. How many participants did you recruit? ____

2.Did that number meet your needs and expectations?

☐ Yes

☐ No

☐ Other (please specify): ____

Then, you may want to reflect on and identify all the relevant outputs of your project.

List the final outputs of your project (e.g., survey, published scientific paper, media interview).

3.Final outputs
1. 2. 3. 4. 5. (Add as many as you like and/or are applicable)

Think about how you have put your data into action.

4.Have your findings served or influenced a specific regulation, changes in policymaking, prompted changes in standards of care, informed care pathways, helped identify relevant outcome measures, etc?

☐ Yes

☐ No

☐ I don't know

5.What have you done or are planning to do?

☐ Schedule meeting to discuss findings with decision and policymakers or regulators

☐ Schedule meeting to discuss with healthcare providers, clinicians

☐ Schedule meeting to discuss with industry

☐ Other (please specify): ____

☐ I am not planning to take any actions to implement my findings

☐ I think this is not applicable in our case

6.Why? (Please justify your choice)

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Finally, it is time for you to make a global analysis of your experience.
Rate your degree of satisfaction with different steps, list and reflecting on the challenges and solutions.

7.Please rate (by marking with an X) **the following options on a scale of 1** (not satisfied at all) **to 5** (extremely satisfied)**.**

How satisfied are you with:	1	2	3	4	5
Your team					
The number of participants					
Your data collection tool and method					
Your data analysis and interpretation of results					
Your result dissemination strategy					
Your results					
The overall project					

Did you experience any (particularly relevant) challenges and come up with solutions to address them? List your challenges and solutions so you can use them as learning lessons and best practices. This can help you in future projects.

Challenges	Solutions

Additional reflection space: If you have any other thoughts, reflections, or comments, you can add them here.

Let thoughts run free!

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Congratulations, you did it!

Every project brings us answers (and since you planned it so well, we are sure it brought you many helpful ones). Listening to and acting on your community's needs, preferences and priorities takes time. It is an ever-evolving process.