

An Introduction to Designing Surveys

Jessie Dubief

SURVEY DESIGN

A survey is a process that includes several steps, and the most important is to make sure that each step is relevant to answer your research questions.

1. Preparation

What do you want to know? For what goals? What is your target population? Does the information already exist? Can you join forces? What are your resources?

2. Data collection

How to best collect information? How to reach out to respondents?

3. Dissemination

How to follow dissemination?

4. Analysis

Who analyses the results and how?

5. Making the most out of the results

How to communicate the results? How to use results / information?



1. PREPARATION

What do you want to know? What are your research questions?

Make a list of questions you want to know the answer to.

For what goals and objectives? Who is your target audience?

Ex: involve your members, shape / improve your organisations' strategies, collect unmet needs, have an evidence-based advocacy (towards decision-makers), shape healthcare activities (involving clinicians and HCPs), assess and improve patient experience (PREMs), care outcomes (PROMs), peer-reviewed article...

Does the information already exist?

Scientific literature ([PubMed](#), [Google Scholars](#)), grey literature (Internet search, specialists), [Rare Barometer surveys](#) (asking for specific results of previous surveys, participating in ongoing or upcoming surveys)...

Can you join forces?

Especially on cross-cutting issues (find other POs to work with, be part of a Rare Barometer survey).

What are your resources?

Budget, human resources, competences... What can you do with few resources? Can you ask for help (ePAG representatives, methodologists...). What is the scale of your project?

2. DATA COLLECTION



Questionnaire

List of questions (close- or open-ended) that allows to **measure** a specific phenomenon.

It is part of the quantitative methods in social science, along with other methods allowing to measure a social phenomenon, either directly (counting...) or indirectly (use of databases...).



Interview

Most of the time, semi-structured interviews = meeting in which the interviewer does not strictly follow a formalized list of questions but uses a guide with open-ended questions allowing for discussion.

It is part of the qualitative methods in social science, along with observation, archive analysis or other types of interviews.

SAMPLE

Population

All the people you intend to know about.

Ex: all PLWRD, all patients living with Duchenne Muscular Dystrophy, all carers of patients living with NF1, patients between 12 and 25 y.o., etc.

Sample

People who participated in your survey (only part of your population):

- **Representative sample**, supposes to know the structure of the population – not usually the case for rare diseases.
- **Purposeful sampling**, where the sample structure depends on research questions and known characteristics of the population.

> Depending on your goals and your target audience (peer-reviewed article...), you should ask for a professional help (social scientist / statistician / methodologist...).



QUESTIONNAIRE DOS AND DON'TS



Do not confuse:

Research question(s) = questions you ask yourselves (and not respondents).

Ex. "What are the most impactful factors on the length of the diagnosis journey?"

Questions that appears in a questionnaire or an interview guide, answered by respondents.

Ex. "As far as you remember, when did you or a healthcare professional first notice the symptoms of the rare disease or think that something was wrong?";

"As far as you remember, when was the name of the rare disease, syndrome or malformation CONFIRMED by appropriate genetic, clinical, medical imaging, molecular or biochemical tests (e.g biopsy, blood or urine test)?"

...



QUESTIONNAIRE DOS AND DON'TS

Make sure that the questions you ask allow you to distinguish your:

Statistical unit

Unit of observation or measurement for the data.

It will be the subject of your sentences when analysing the results.

Ex. all PLWRD? Only patients? Only caregivers? One visit to a hospital (then one person can assess several visits)? ...

Variables

A person (or their characteristics), place, thing, or phenomenon that you are trying to measure in some way.

Ex. age is a variable.

If you ask: "How old are you?", then the variable is also the question.

If you ask the date of birth and then calculate respondents' age at a certain date, then you have a calculated a variable based on two questions (two dates).



QUESTIONNAIRE DOS AND DON'TS

Only one question per question

Ex. there are two questions in “does your doctor ensure follow-up after visits and have good communication skills?” and you will not know which question respondents answered.

Translate the questionnaire in your native language

You will notice imprecisions you may not have seen otherwise.

Use simple and understandable language

When technical language is unavoidable, try to explain it as much as possible in the question itself or in a guideline that will be just under the question.

Prefer using positive phrasing

Propose as many “positive” and “negative” items to a question

Choose the most appropriate format for each question

3. DISSEMINATION

How to best recruit participants?

Online: easier to reach out to more people, especially when they are geographically spread, but respondents need to have access to the internet and numeric literacy. Less expensive.

On-site: easier to diversify the sample, but more expensive (someone to distribute questionnaires and enter questions). Can include costs to rent a tablet.

Be mindful of the **social characteristics of respondents** (probably more educated, usually more respondents in Western Europe, more engaged...).



4. ANALYSING RESULTS

Who analyses the results and how?

How much time will be needed?



4. ANALYSING RESULTS

Descriptive statistics

Summarize a given data set, e.g. a sample if the sample is not representative; a population if the sample is representative.

It can include: frequencies (number of answers to one question / variable / item), percentages, measures of central tendency (mean, median, mode) and measures of variability (or spread: standard deviation, variance, minimum and maximum).

Analytical statistics

Crossing two or more variables to see which relationship exists between those variables (and their items): cross tables, correlation, multivariate analysis...

Statistical tests

Describe how much the relationship between two or more variables is statistically significant = more or less likely to be due to chance.

Compare with existing results (when comparable)

Discuss results with other groups / focus groups



4. ANALYSING RESULTS

ONLY SAY WHAT YOUR SURVEY DESIGN ALLOW YOU TO SAY

When you write and communicate on the results, be mindful of your **statistical unit** (patients / carers / respondents / hospital visits...) and on the **structure of your sample** (and what it allows you to say).

Only communicate on **significant** results.

Interviews and open-ended questions: thematic analysis, quotes...

Always give a **feedback** to respondents and/or people interested in the survey (e.g. who helped disseminate it, who may benefit from it...).

Adapt to your target audience:

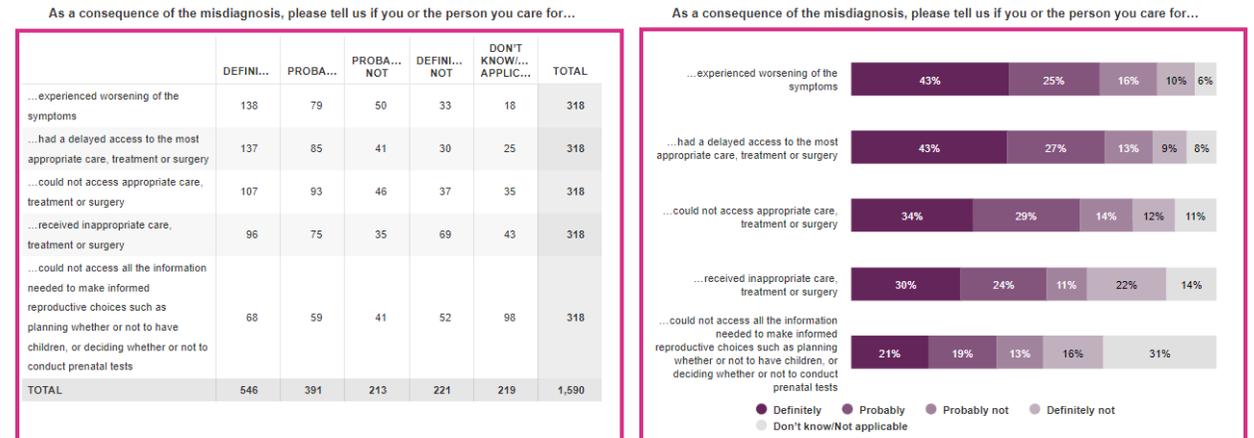
- Patients (members)
- Advocacy goal (decision-makers)
- Scientists (peer-reviewed article, communication)

5. MAKING THE MOST OUT OF THE RESULTS

Format (adapt to your target audience):

- **Dashboard** (results for each question)
- Factsheet / infographics (key results)
- Peer-reviewed article
- Communication: face-to-face, webinar, video presentation of the results...

DASHBOARD



For each question of the survey:
Number and percentage of responses to each item

5. MAKING THE MOST OUT OF THE RESULTS

Format (adapt to your target audience):

- Dashboard (results for each question)
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FACTSHEET /
INFOGRAPHICS



MEJORE NUESTRA EXPERIENCIA SANITARIA



3905 personas con enfermedades raras indicaron cuál había sido su experiencia sanitaria mediante la encuesta H-CARE de EURORDIS-Rare Diseases Europe entre diciembre de 2019 y marzo de 2020

1 LA EXPERIENCIA SANITARIA DE LAS PERSONAS CON ENFERMEDADES RARAS

Los pacientes con enfermedades raras dan a la atención sanitaria una calificación baja

Los pacientes con enfermedades raras puntúan de media su experiencia sanitaria...



en una escala del 1 al 5

Los pacientes con enfermedades raras parecen tener una experiencia sanitaria peor que los pacientes con enfermedades crónicas: el 70 % de los estudios que utilizaron el mismo cuestionario notificaron una puntuación media más alta en la experiencia sanitaria de los pacientes con enfermedades crónicas**.



La puntuación de la experiencia sanitaria media se obtuvo combinando las respuestas a 11 preguntas relacionadas con el seguimiento tras las consultas, la información sobre los tratamientos, la coordinación asistencial o el modo de abordar su salud en el día a día.

5. MAKING THE MOST OUT OF THE RESULTS

PEER-REVIEWED ARTICLE

Format (adapt to your target audience):

- Dashboard (results for each question)
- Factsheet / infographics (key results)
- **Peer-reviewed article**
- Communication: face-to-face, webinar, video presentation of the results...



The screenshot shows the Orphanet Journal of Rare Diseases website. At the top, the journal's logo and name are displayed. Below the navigation bar, the article title is prominently featured: "Share and protect our health data: an evidence based approach to rare disease patients' perspectives on data sharing and data protection - quantitative survey and recommendations". The authors listed are Sandra Courbier, Rebecca Dimond, and Virginie Bros-Facer. The article is from the 14th issue of the journal, published in 2019. It has received 8991 accesses, 25 citations, and 70 Altmetric mentions. The abstract section is titled "Background" and discusses the importance of sharing health data for scientific research and clinical benefits, particularly for rare diseases where knowledge is limited and patient populations are geographically dispersed. It mentions that EURORDIS-Rare Diseases Europe regularly surveys the rare disease community to identify their perspectives and needs.

5. MAKING THE MOST OUT OF THE RESULTS

Format (adapt to your target audience):

- Dashboard (results for each question)
- Factsheet / infographics (key results)
- Peer-reviewed article
- **Communication**: face-to-face, webinar, video presentation of the results...



SUM UP OF RARE DISEASE SPECIFICITIES

Sample size and **population size**

Sensitive data: [article 9](#) of GDPR

Anonymity: when presenting results, make sure that the characteristics you give for your respondents does not allow to recognize them, especially when populations are small (few patients in one country...).

Samples are usually not representative: only talk about respondents for descriptive statistics (not about the whole population) and use significant data for analytical statistics.

During results analysis and communication, **the subject of your sentences should correspond to your statistical unit:** respondents / patients / carers / people living with rare diseases...

Respondents are usually contacted through patient organisations, and online: be mindful of the **social characteristics of respondents** (probably more educated, usually more respondents in Western Europe, more engaged...).

⚠️ SURVEY FATIGUE