



SUPPORTING HEALTH DATA INITIATIVES: SHOULD YOU ENGAGE? A RISK ASSESSMENT TOOL FROM DATA SAVES LIVES

As a patient group or individual advocate, you may occasionally be approached by third parties to support or be involved in a health data initiative or initiatives. This is entirely natural – after all, your members or network can offer valuable ‘real-life’ insights into living with specific diseases and can suggest how improvements could be made in healthcare delivery.

These third parties could be public or private institutions. They could include pharmaceutical companies, healthcare facilities, clinicians, government bodies, academic institutions, commercial technical companies (e.g. app developers) healthcare organisations, research institutions or other patient groups.

Taking part in such initiatives could have a number of advantages.

- It could help to raise your profile or allow you to develop a positive relationship with an influential third party.
- It could increase knowledge about the area you are involved in or facilitate access to support or care for your members.

However, before you sign on the dotted line, it is important to be fully aware of what you are committing to. How will this venture impact your community and your organisation’s reputation? Are there any potential risks or disadvantages?

This tool from **Data Saves Lives** provides a risk assessment framework so that you can assess the pros and cons of any potential project and, if you decide to proceed, allow you to engage in a more confident and informed way.

What are the opportunities for engaging in health data initiatives?

The possibilities range from simple sharing of information among your members to close involvement in the development of a new digital health tool. Examples include:

- Sharing an online survey with members and encouraging them to participate
- Supporting the development of a new patient registry or greater involvement in an existing one
- Promoting an app among your members and encouraging uptake
- Involving your members in the development or assessment of a new health app
- Sharing or selling data from an existing database of members.

The value of involving patient communities in digital healthcare design

According to research, patient needs are not always taken into account during the design of digital health tools such as apps and usage is often lower than expected: typical medical or fitness apps have a 90-day retention rate of just 27–30%. To create relevant, usable and effective digital health, it is critical to increase patients' involvement in the design of technological tools.¹

Before you commit to any project, it is important to ask some **key questions** first to ensure that you have a clear understanding of what is being proposed. These will not all be relevant to each type of initiative but they provide a starting point for discussions.

The basics

- Exactly what does the project involve – what is its aim and what are the expected outcomes?
- Precisely what are you being asked to do? Has it been set out in detail and do you understand what is being asked of you?
- Is there any financial remuneration and if so, is this at an appropriate level? Fair market value (FMV) may differ from country to country. How and when will payment be made?
- How much of your time will the project involve? Do you have the capacity to devote this time to the exercise? Will you need to be involved personally?
- Who will be your point of contact?
- Will you be updated as the project progresses?
- What is the timescale?
- How will your organisation benefit from involvement? Will the project provide relevant data and will this be shared with you? Will it empower your members in any way or lead to the development of a tool that could be beneficial to them?

How will this exercise reflect on you and your organisation?

- Will your involvement be made public? How will this be done?
- Will this have a positive impact on your profile, for example by positioning your organisation as forward-thinking or innovative?
- Could there be any downsides, e.g. perceived influence from third parties that could affect independence/credibility?
- Will you have the option to see any materials relating to the project you are involved in before they are published?
- Who will have the copyright to the material?

“Many companies have developed new ways to incorporate patient insights and to collaborate with patients and patient organisations in a transparent and ethical way. This has led to better trials, better engagement, better communication throughout the entire life cycle of medicines – and ultimately better patient outcomes”

European Federation of Pharmaceutical Industries and Associations²

Safeguarding privacy

- If your members are being asked to contribute data, how will this data be used? Will it be shared with third parties?
- Will the data be anonymised?
- Will you have access to the full set of data?
- If you are considering sharing or selling member data, has this been made clear to members in your Privacy Policy? Could this impact their trust in your organisation?

Before you go ahead

If you decide to proceed with a health data initiative with a third party, there are a few final points to consider.

- How much information do you need to provide to your members?
- Do you need to make a more public declaration? For example, if you are working with a pharmaceutical company it is important to be transparent about this, particularly if you are receiving payment of any kind.

If the third party you are engaging with is not able to answer your questions fully or you feel uncomfortable with any aspect that is being asked of you, it may be wiser not to proceed or to take some time to consider your options. Do not feel pressured into taking part. The potential benefits of involvement in a joint health data initiative are significant, but there are certainly downsides to consider.

Below is a table which you can use to record your thoughts on a project and keep them for future reference.

Project details	
Level of confidence on scale of 1–5*	
Comments/further action needed	
Additional comments/final decision	
<p>*Confidence level</p> <ol style="list-style-type: none"> 1. Not satisfied with answers to questions/insufficient information to make an informed decision 2. Some areas of interest but significant additional information/reassurance required 3. Promising proposal but additional information/clarification required 4. Largely satisfied with proposal, clarification on final points appreciated 5. Fully satisfied with proposal: willing to proceed 	

References

1. Patient Engagement and the Design of Digital Health - Birnbaum - 2015 - Academic Emergency Medicine - Wiley Online Library
2. working-together-with-patient-groups-23102017.pdf (efpia.eu)