PATIENT IN FOCUS

Patients as partners
Agenda

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- Patient recruitment
- Patient roles in R&D
- Patient engagement
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Patient in Focus is an international, nonprofit disease neutral patient organization built by patients for patients.

- Disease neutral because patients experience the same emotions and challenges across all diagnoses.

We understand patients because we are patients.
Disease neutral

Patient in Focus has relationship with:

- >22,000 patients
- 90 different countries
- 120 diagnoses

We work with all types of patients and their relatives and caregivers.
Mission – for patients

Patient in Focus improves the living conditions for patients through Knowledge – Tools - and Education so that patients can lead a life of quality despite illness, pain, and disability.
Patient in Focus assists patients in leading lives of quality by providing them information and tools for success.

We include patients in patient engagements where the patient perspective can be of great value and help them find clinical trials they can join.

We are the liaisons between patients and companies, ensuring that our patients have all the support they need without the administrative burden.
Mission – for professionals

Patient in Focus helps other patients get involved with patient engagement, research etc. and thereby give the professionals the knowledge they lack.
Not your average organization

We are a unique patient organization and recruitment service in one personalized, trustworthy, patient-to-patient package.

We help you with everything related to patients:

- Knowledge
- Access
- Facilitation

to ensure all patient recruitment and engagement projects are successful.
Patients are our number one

Working with Patient in Focus means patients:

- feel safe and comfortable
- remain anonymous
- gain support and protection
- avoid administrative burden

We protect the patients first and foremost by acting as the patient-client liaison to ensure patient comfort and optimal client interactions.
Patient recruitment

We builds relationships on trust and real connections

- We are not a typical recruitment agency or registry without real contact. We pride ourselves with having personal interactions with our patients. We don’t just send out an email, we talk to people.

- Human interactions generates relationships. Patients trust patients – there is a common understanding you can’t get from a regular recruitment agency.
Patient access isn’t a problem, it is a huge problem.

To reach the targeted number of patients for patient engagement or study recruitment, you must have a large reach.

We make the unattainable patients, attainable.
Patient roles in research and development

Patients have two essential roles in R&D:

- Clinical trial participation
- Patient engagement

Patient in Focus is your patient recruitment partner for clinical trials, studies, and patient engagements.
Why engage patients?

To understand the diverse needs of patients and hear their unique experiences, knowledge and perspectives that can contribute to essential evidence for industry-led research and development, you must engage patients.

Patient contribution can confirm aim, ensure product/service usability, and solve access challenges.
By engaging patients prior to trial start, you can:

- eliminate patient recruitment challenges
- identify gaps and areas of improvements
- ensure the trial design makes sense for patients
- confirm patient burden is acceptable
- verify patient trial value
- establish adherence procedure
- check the inclusion/exclusion criteria
- create appropriate layman’s terms documentation
- assist with appropriate marketing strategies
When to engage patients in R&D
Making a difference

Your **guide** to the patient world.

- If you make shaving cream, you ask a beaded man for his opinion. When producing baby formula, you involve a new mother. If you make anything for or about the patient, you must ask the patients.
- If you do not understand the mindset of the patients, how will you be able to make a difference in their lives?
- Including patients in the co-creation of medications can make a huge difference – for patients and for you.
Patient engagement

The sooner you engage patients, the better.

There are no limitation to when and how you can include patients.

- Patients must be part of all patient related projects to ensure authenticity, understanding and relevance - from thought to end of lifecycle.

- You cannot include patients too soon.
If you want to know the truth, ask a patient.

Only patients truly know what patients think

- Avoid surprises
- Collaborate
- Co-create

List of services

Patient in Focus services to include:

- Awards judges
- Advertisement
- Beta testing
- Caregiver/relative interviews (facilitation/participation)
- Caregiver/relative recruitment
- Clinical trial volunteer recruitment
- Ethical review
- Evaluations (i.e. grants, hackathons, competitions)
- Grants application evaluation (prior to submission)
- Health tech review
List of services

Patient in Focus services to include:

- Patient engagement recruitment and coordination
- Patient events (coordination/facilitation/participation)
- Patient influencers campaigns (marketing distribution)
- Patient reported outcomes (PRO)
- Product and service testing
- Publication co-writing (articles, medical journals, etc.)
- Secret shopper (i.e. patient access services, B2C, etc.)
- Steering group representation
- User guide (creation/review)
It took a lot of time for developers to create a health app adherence tool. The company didn’t engage patients in the development process but instead waited until at point of launch. Unfortunately, the patient findings deemed the app unusable because it contained serious mistakes, wasn’t thought out, wasn’t user-friendly, and made no sense for the patients. A year and €1M wasted.

A patient advisory board setup was completely wrong. An abundance of professionals in the room asking leading questions while surrounding the 5 patients, who felt intimidated, uncomfortable and coerced into saying something they didn’t mean. The professionals got what they wanted but it wasn’t the truth and hence they developed something the patients didn’t need or want.

Patients pay for your mistakes!
Patient engagement done right

After months of no response from patients, Patient in Focus reviewed the survey questions, which showed that the endpoints were unsustainable. After the questions were rewamped, made measurable, and sent to our patients, the researchers received 350 responses in just 2 weeks, 755 responded in total.

A phase 3 clinical trial had been withdrawn due to inability to recruit participants and noone understood why. Patient in Focus discovered that the trial design was unethical. The mandatory requirements were too demanding and painful, and the voluntary requirements were too many, too burdensome, and too painful.
Patient engagement done right

The patients projected that max 1% of the trial participants would complete all of the voluntary requirements and therefore would cause unnecessary pain and suffering without cause because there wouldn’t be enough data to compare with. The trial design was redone with patients as co-creators and they were finally able to recruit patients.

Researchers needed to conduct patient interviews as part of a study. Patient in Focus convinced the researchers to let us do some of the interviews and thereby proved that the answers were completely different. They gained greater insights and more honest answers when a patient asked another patient questions vs. a professional, who had made a career doing patients interviews. They were surprised to see how much of a difference it made and asked Patient in Focus to conduct all study related interviews in the future.
Only then you think it is too much, is it enough.
Patients for patients

Patient in Focus has a unique collaboration with patients across disease areas.

We **handhold** our patients because they prefer it.

To ensure the patients feel safe and comfortable, Patient in Focus will:

- Coordinate
- Guide
- Pay
Patient contribution

Our patients *WANT* to work with you, guide you and give you the insights you are need.

They understand that if they assist you, you will essentially help them, too.
Summary

Patients suffer from the choices YOU make (or don’t make).

- It’s not about you and them. It is all about the co-creation.
- Treat patients as if they were your most precious customer, because they are.
- Engage patients from thought to end of lifecycle to avoid surprises and costly mistakes.
Contact information

To discuss your patient needs contact:

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