

**YOU THINK YOU KNOW
THE **PATIENT** INSIDE-OUT.
BUT DO YOU KNOW THE
OUTSIDE-IN?**



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Are we seeing the patient's world as clearly as we possibly can? Will a more complete picture help us to build better brands?

In business, making assumptions can be an important first step to solving problems. But it can also bias us in how we frame the challenges, the questions we ask, and the decisions we make. It's the same for healthcare market research and pharmaceutical interactions.

The way we think about individuals living with illness, and how we design research and create solutions can be led by our own biases and assumptions about people. For example, as stated by Lorraine M. Thirsk (2014): "The focus on 'self' in 'self-management' can lead us to think about chronic diseases as a largely independent activity and that people require individual solutions."

In addition, the word 'management' implies there is a set of strategies that everyone can work with consistently and effectively.

When designing research methodologies, we tend to zoom in on the main characters to learn about their experiences; the person living with the illness, the physician...maybe even the carer or the nurse.

And when understanding prescribing behaviours, we focus in on the physician-patient consultation. But what if this 'individual focus' is not telling us the whole story? Do we miss out on a valuable part of the story? Are the missing pieces key to the research objectives or to the brand we are helping to build?

An individual focus may not be accurate. Chronic diseases can be viewed in a more connected sense, "embedded in family, community and societal conditions that shape and influence" (Kendall, 2010).

Furthermore (paraphrasing Fritz Heider), we are all unreliable witnesses of our own behaviour. This is complicated further with the emotional burden for people living with an illness, impacting what they are able to recall and sharing with us only what they believe we want to hear.



Challenging an 'island view'

At THE PLANNING SHOP, we have been conducting research to challenge what we call an 'island view' of the patient, by introducing 'witnesses' to our studies.

These are the people who are usually absent from research, but who have an important perspective and can potentially influence management and treatment. Taking severe haemophilia as an example, we recently completed a piece of UK qualitative research to see if 'witnesses' add value to patient research. We included witnesses to help us build a more complete picture and uncover deeper insights that we believe can lead to more effective brand building.

From the outset we chose a more open approach to the study, enabling us to include a wider range of roles – clinical and non-clinical – who we would not normally speak with. The recruitment process involved:

- ▼ Mapping all potential touchpoints of a person living with haemophilia (people considered to be in their team)
- ▼ Use of descriptive statements in the screening materials to describe the potential influence and involvement of 'witnesses' as well as the 'main character' roles
- ▼ Inclusion of a diverse sample of individuals viewing the haemophilia experience from different angles.

Our methodology included the use of indirect questioning, self-discovery exercises and challenging different team members with different viewpoints. We explored the most important connections and relationships with remote and live in-home discussions to build both depth and breadth of understanding.

Before we move onto the research outcomes, let's talk haemophilia. What is it?



Haemophilia: Invisible. Unpredictable. Malicious.

Haemophilia is a rare, usually inherited, genetic disorder that inhibits the blood's ability to clot, with types A and B affecting different clotting factors. 2017 UK annual data shows 9,639 people (mostly males) living with haemophilia in total, with 2,295 severe cases. These numbers exclude female carriers who may also have symptoms, and the wider sphere of different family and friends for whom haemophilia impacts.

Haemophilia can be described as:

Invisible: bleeding is the most identifiable sign, but it is often accompanied by chronic joint pain and psycho-social issues. The combined limitations and lack of wider community understanding can make haemophilia anti-social and isolating, lending a wider meaning to 'invisible'

Unpredictable: even the most experienced person cannot always anticipate when or how haemophilia will strike; a repetitive task at work, a night out with friends, a simple knock at home or a trip on the pavement

Malicious: one day you might be busy with life, the next day you could be temporarily debilitated in a wheelchair, interrupting important plans and quality of life.

An underlying tension in the world of haemophilia

With treatment advances – such as self-administered factor infusions – haemophilia care has moved from the hospital into the community. Comprehensive Care Centres (CCCs) with in-house multi-disciplinary clinical teams including the haematologist, specialist nurse and physio (and psychologist in larger centres), are now providing hubs of expertise designing treatment and management plans, where people living with haemophilia can self-manage in the community and live their lives.

However, our research uncovered an underlying tension in haemophilia: living an independent life and self-growth, in a medicalised system. A tension which results in an ongoing risk-benefit gamble for patients and carers throughout their lives, with people asking themselves questions like:

- ▼ “Is it worth the risk of a bleed or chronic joint and pain issues?”
- ▼ “Shall I follow the rules?”
- ▼ “Who am I?”

Our research has shed light on how people living with haemophilia find their way around this tension.

Research outcomes

Insight one: Identity and tackling the lion

To begin to explain this tension we need to tell a story about Hercules.

Nemea the lion was a vicious monster in Greek mythology and Hercules had a huge task to conquer Nemea. After much persistence Hercules killed the lion with the force of his hands. Once dead, he removed the skin of the lion and used it like armour, making him invincible. In psychological terms, to fight the lion means to face our deepest fears, but to accept our weaknesses as part of our identity (wear the skin) is to be transformed.

Interestingly, the goal of being brave and wearing your haemophilia with pride is what the HCPs we spoke to try to inspire people living with haemophilia to do. Role models such as some patient influencers wear their haemophilia in a similar way. Take Christian L Harris for example, whose own severe haemophilia has inspired his fashion designs. Or Chris Bombardier who is raising awareness by completing the seven summits challenge with severe haemophilia.

But is this a realistic and desirable goal for all people with haemophilia?

We see there are different and overlapping paths taken by people living with the disorder:

- **The regular guy:** through adjustments and adaptations haemophilia is kept in the background and does not play a starring role. A sense of wellbeing and belonging is achieved
- **Social withdrawal:** on the journey towards being a 'regular guy,' patients can be derailed by the limitations placed on them by the disease leading to social withdrawal and isolation
- **Low self-worth:** their personal identity can be consumed by the negative associations of haemophilia and they can experience a loss of self-worth.

Those who have been affected by the contaminated blood crisis in the 1980s and blood borne viral illnesses may be particularly prone to the 'cul-de-sacs'.

The paths for someone living with haemophilia are not consistent or straightforward, which lends value in understanding the perspective of 'witnesses' who accompany them in their world.



Insight two: The haemophilia team

The people with haemophilia in our research acknowledged that a team of individuals surrounds them. One person told us that he and his team collectively form “one functional person”. When observing the carer parent (typically Mums) and child team versus the adult team, we noticed that they are different in size. The parent and child teams tend to be large and varied. Adults have a smaller and intimate team. During clinical transition (from paediatric to adult care), teens and young adults leave behind what was their parents’ team and build their own trusted team from scratch.

Romantic partners or best friends are often the adult patient’s most influential team members – more so than the medical team. This team evolves over time through the course of different life events (e.g. relocating, marriage, having children etc). A partner or a best friend (unlike the medical team) can be confided in over the long-term, offering regular emotional and practical support.

Our research showed that the clinical team, however, perceived things differently. They acknowledged that the person living with haemophilia has a team surrounding them, but they over-estimated the influence of wider friends, immediate family and independent organisations or charities rather than the trusted team. How does this happen? People living with haemophilia stated how wider friends and immediate family “don’t get it,” organisations don’t offer valuable support locally, or they are comfortable with others not knowing too much because it creates too many questions and distractions from their everyday lives. There may also be geographical, cultural and religious reasons for people not being open about their health status.

Importantly, the clinical team over-estimated their own influence, believing they offer more emotional support than people with haemophilia think they do - sometimes under the guise of education.

There are three core reasons for these disconnects and tensions from a clinical perspective:

1. The geographical distance of CCCs from people living with haemophilia and their families and once or twice-yearly face to face interactions with the clinical team





2. The physician focus on clinical aspects: 'blood and joints' and the assumption that haemophilia is 'manageable' for everybody
3. Simultaneous trust and distrust: trust in medical expertise, but lack of trust in the medical team's understanding of their lives and desires as a person.

The reality of living with haemophilia is complex. Patients surround themselves with a trusted network of individuals. Speaking with these team members is vital to understanding how people navigate their world with haemophilia.

The clinical perspective is not sufficient for understanding this. The most critical team members are a subset of all the witnesses we spoke to and represent a new target for research and brand building – the 'Outside-In'.

Insight three: The unique perspective and influence of the 'Outside-In'

The 'Outside-In' team members of the person living with haemophilia or parent carer:

- ▶ Are not necessarily part of the multi-disciplinary clinical team or part of family or friends
- ▶ Have come from the outside and are now on the inside, meaning they are able to give a fresh perspective on haemophilia (e.g. a new romantic partner)
- ▶ Know the person living with haemophilia or parental carer inside-out.

In our research we identified many examples of 'Outside-In' team members – these individuals are in a unique position to not only share their view of the person's world and experience, but also to take an influential role and effect change.

An example of an 'Outside-In' team member who took part in our research is Sarah:

Sarah is the relatively new partner of John who lives with severe haemophilia. As part of the research we conducted in their home, the couple shared some interesting anecdotes:

1. Sarah activates and augments John's engagement with treatment. In discussions, John compared his adherence to treatment before and after they met:

"I know sometimes they [the bleeds] go untreated – I would say that's quite rare now... 10% would get treated previously, and 10% might be left untreated this time round."

2. Sarah takes an ongoing role in monitoring and communicating John's treatment via a haematology app called the Haemtrack app. John takes a more passive role. He said:

"I wouldn't do that. I'd forget to be quite honest. So you've [Sarah] got it on your phone. I haven't got it on my phone."

Sarah also helps to filter information to John in a way she knows is digestible from sources online and by being an active member of the Haemophilia Society (unlike John).

3. Haemophilia is not just about looking out for the immediate patient. It's about future generations too. During discussions Sarah dropped the word 'daughters' into a conversation with John's long-term haematologist. This was planned to have a domino effect. Sarah had previously recognised that John's daughters from a past relationship were carriers of haemophilia. They all knew this, but there were no proactive conversations going on. John believed:

"It would have been on the [medical] record, but then it just gets lost."

Sarah clarified that a conversation with the doctor would never have been prompted by John or his doctor without her and said:

"Because of my career (as a healthcare professional), I know what questions to ask... maybe nobody else would."



As a direct result of Sarah's intervention John's daughters are now receiving adequate information on haemophilia and available treatments and can start to plan their own families.

Sarah's anecdotes show that the 'Outside-In' are highly conscious of the person's experience and are influential within their world. We identified many other individuals like this, clinical and non-clinical.

For example, a support worker who had a unique birds eye view of the multi-disciplinary team, and who also had a view of people who would never usually take part in market research, and a young man having social and housing issues who retreats to online gaming to actively avoid managing his haemophilia.

In summary the 'Outside-In':

- ▼ Create positive adjustments and adaptations to the person's lifestyle
- ▼ Are highly engaged and influential in treatment and management
- ▼ Enable the people they care about to live in the moment rather than reflect negatively on the past or worry about the future.

Ultimately the 'Outside-In' are creating resilience and ongoing functional wellbeing – more complex than simply emotional or practical support. As time moves on they expect to have an increased role in the lives of the people they support with haemophilia.

We have picked out this specific group of individuals because they are significant influencers and could help us to piece together a more accurate picture of the patients' experiences. Other team members were valuable to speak with as well – especially in collaboration with the person living with haemophilia. For example, where the individual with haemophilia wasn't able to express themselves, the team member was able to fill in the gaps. Simply their presence in the conversation and acknowledgement of the issues led to more natural and collaborative discussions.

Importantly, by speaking with the 'Outside-In' and other team members, we were able to gain a more complete picture of the person's experiences with haemophilia and understand how the important

tensions in haemophilia mentioned earlier are currently being navigated, serving as a solid platform for communications and solutions generation.

Our findings raise important considerations for the clinical approach to haemophilia care in the UK National Health Service (NHS). The focus on independence and self-management doesn't necessarily reflect the reality of what management in the community entails.

There is potentially a need to re-think how clinicians can support and engage in the person's world via their haemophilia team (as long as privacy considerations allow). For example, adults who wish to bring their team into the relationship with the clinical team should be encouraged (not judged by the clinical team), because team members can add valuable insights impacting personalised treatment and management decisions. It is also important to note that there is a tipping point for new and innovative treatments – for example, will less need for hospital delivered care lead to more isolation for haemophiliacs?

Outcomes and ideas

Patient world

Brand engagement has come a long way since sales representative product messaging to physicians. We have started to acknowledge patients as engaged and influential people in treatment and management. It is now time to zoom out to reveal the world of the person – a wider web of social interactions and situations – a more complex system of decision influences and triggers. We believe this broader picture is currently an untapped resource of experiences and insights across therapy areas.

Solutions driven by the 'Outside-In'

We have learned that the 'Outside-In' team have a transformational effect and are important influencers in the world of the person. We suggest brands tap into the problem-solving skills of the 'Outside-In' for solutions and ideas generation. As experts in the desires and quality of life of people who happen to have an illness, and with experience

in creating lifestyle adjustments, the 'Outside-In' can help brands develop solutions that connect better, are more sustainable and work beyond an individual level.

Diverse brand engagement

Brands need to be able to engage with multiple team stakeholders and evolve tactics across life stages with channels and messages tailored to the right people at the right time. When services are being created, pharma brands need to be conscious of 'connectability' and input from wider team members. For example, brands can create campaigns like Alzheimer's brands and charities that recognise the importance of the role of carers and families. This idea can be built upon even further; taking inspiration from consumer brands like Kraft and Premier Foods who are using insight gained from family, friends and communities to create campaigns and tactics that are tapping into the desire of connecting people together. One example is the Bisto 'Together Project', highlighting loneliness with their 'Spare Chair Sunday' project and bringing friends and family back together who have lost touch.

Communications through the lens of life

We encourage brands to create a new language to be more relatable. Patients are people living with an illness. Creating higher purpose and communicating through the lens of life will create stronger positionings and differentiation in crowded and clinically focused markets, ultimately building trust. This is whether it's helping the clinical team to quickly understand the person's context and desires in consultations to create tailored solutions or creating resources that move beyond educating about narrow medical moments to instead helping people to live their lives better.

It is a new era. We need to zoom out to understand the person's world and experiences as clearly as we can. We need to understand all of the factors that influence them within their context. We need to use the 'Outside-In' to create valuable brands that speak to the people that use them.



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References

Kendall, P. (2010). Investing in Prevention: Improving Health and Creating Sustainability: the Provincial Health Officer's Special Report. Office of the Provincial Health Officer, British Columbia.

Lorraine M. Thirsk, A. M. (2014, Maya What is the 'self' in chronic disease self-management? Retrieved from [https://www.journalofnursingstudies.com/article/S0020-7489\(13\)00283-6/fulltext](https://www.journalofnursingstudies.com/article/S0020-7489(13)00283-6/fulltext)



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