The meaning of personalised healthcare to patients

How good communication underpins positive patient outcomes in oncology and beyond

pharmaphorum media and Inspire

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Executive summary

The confluence of personalised medicine and the digital information age means that a much greater volume of information is required by physicians in successfully treating patients, in addition to the patients themselves becoming more educated about their disease, leading to a more empowered role within the healthcare continuum.

As a result, approaching successful medical intervention purely through clinical metrics and appropriate treatment pathways does not take account of the complex communication dynamics emerging within this new landscape. For successful disease management, patients must fully understand treatment decisions relating to them, and physicians must consequently be able to engage on a more personal level with their patients.

This white paper, produced through collaboration between leading health and wellness community builders Inspire and pharmaphorum media, researches the patient-oncologist relationship from the patient's perspective and explores conclusions for healthcare providers, patients and the pharmaceutical industry.

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‘Personalised healthcare’ is one of the central concepts in modern medicine. However, the term means different things to different people. Among healthcare professionals, and within the pharma industry, it denotes the targeted use of particular treatments based on specific characteristics of the patient or their disease. By contrast, the end-user – the patient – may understand this term in more human terms, referring not just to personalising their treatment but also their interaction and communication with healthcare providers.

Inspire – a US-based online patient community – has teamed up with pharmaphorum media to perform and publish a piece of collaborative research among cancer patients and survivors exploring the interaction and communication they had with their oncologist. The primary focus was on service levels and the degree of personalisation achieved during the first few encounters after diagnosis.

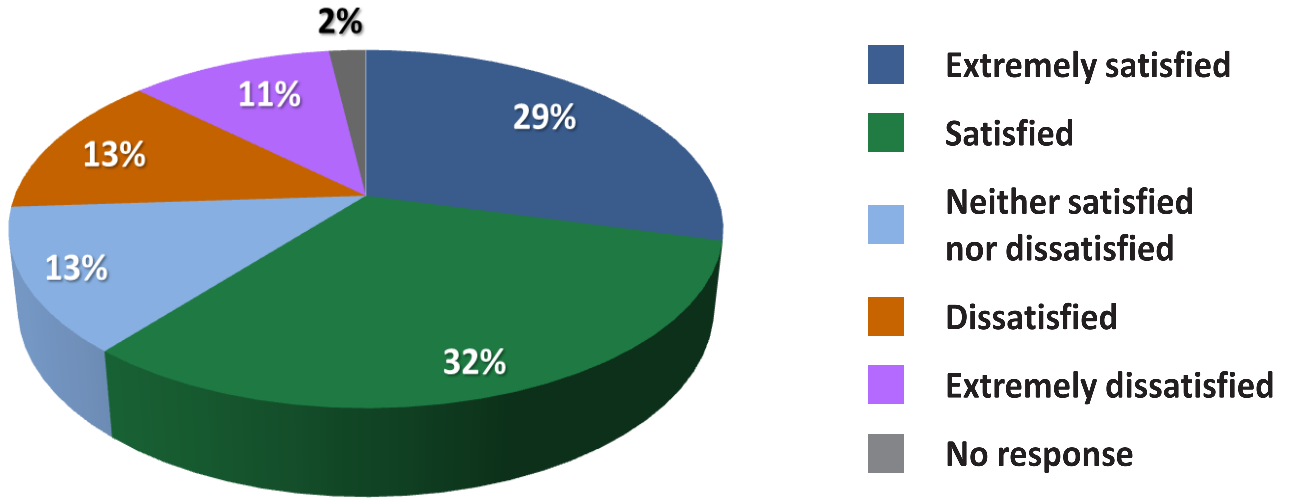
Oncology is an especially relevant disease area for this research, given the emotional sensitivity attached to ‘the C word’ and the unique communication challenges it therefore presents. Furthermore, the complexity and variability of different tumour types, and the variability in the demographic characteristics of cancer patients in general, makes personalised communication particularly essential.

Inspire sent a survey to members of its cancer support communities, and it received 1,301 responses. As shown in Table 1, most respondents were female, and had experienced a wide range of different tumour types. The majority (58%) had already completed treatment.

Table 1: Survey respondents (n = 1301)

Gender		Tumour type		Treatment status	
Female	55%	Thyroid	17%	Not yet begun treatment but plan to	4%
Male	30%	Ovarian	14%	Currently going through treatment	35%
Not stated	14%	Prostate	14%	Completed treatment	58%
		Lung	13%	Cancer is not treatable	2%
		Bladder	10%	Not stated	1%
		Breast	5%		
		Other	25%		
		Not stated	1%		

Figure 1. Patient satisfaction with the interaction and communication with their first oncologist over the first few encounters (n = 1301)



Patients want information as well as medicines

Good patient communication skills have always been important in the medical profession. Previously, these skills were called 'bedside manner' and were largely based around a paternalistic relationship in which the patient was instructed what to do by his / her physician. In the modern day, these interactions are more typically defined in terms of 'physician–patient partnerships' and are based much more on a relationship of equals.

The survey data show that, in broad terms, oncologists are generally doing a good job of engaging with their cancer patients – 61% of patients said that they were extremely satisfied or satisfied with their initial interaction and communication with their oncologist (Figure 1). These numbers were largely consistent, irrespective of patients' current stage of treatment or tumour type.

However, the data do suggest that there may be some differences between men and women in their levels of satisfaction. Only 54% of men with prostate cancer said they were extremely satisfied or satisfied with their initial contact with an oncologist, compared with ≥70% of women with breast or ovarian cancer (Figure 2). Does this mean that men were harder to please? Or, more worryingly, were there gender differences in the way that oncologists communicated with their patients? Either way, it suggests that oncologists may need to re-examine the way they manage their early contact with male patients.

Patients who were extremely satisfied or satisfied with their early experiences with their first oncologist were asked to give their reasons why the interaction was positive (Figure 3). Given the psychological impact of a cancer diagnosis, it is not surprising that the degree of kindness and caring of the physician was a key factor

> *"The most commonly cited reason for a positive experience was that the oncologist took ample time to explain the diagnosis and treatment options"*

(cited by 69% of patients). However, alongside this, several positive factors related to being given sufficient information in clearly understandable terms. Indeed the most commonly cited reason for a positive experience was that the oncologist took ample time to explain the diagnosis and treatment options (cited by 81% of patients). As one respondent noted, "*I came prepared with a page of questions for my oncologist during the initial consultation. She spent at least 30 minutes answering all my questions, and allowed me to express my opinion about treatment options.*"

Another key factor that underlay positive experiences was being included within the decision-making process (53%). Patients no longer want a paternalistic relationship with their physician; they want to be involved, and want to partner with their oncologist to understand and even help to drive their own care. Talking about their physician, one patient said: "*Our relationship has evolved over time and I had to be assertive enough to let him know what I needed. Once we opened up the communication, we became a team.*"

Figure 2. Patients who were extremely satisfied or satisfied with their initial contact with their first oncologist (n = 1301)

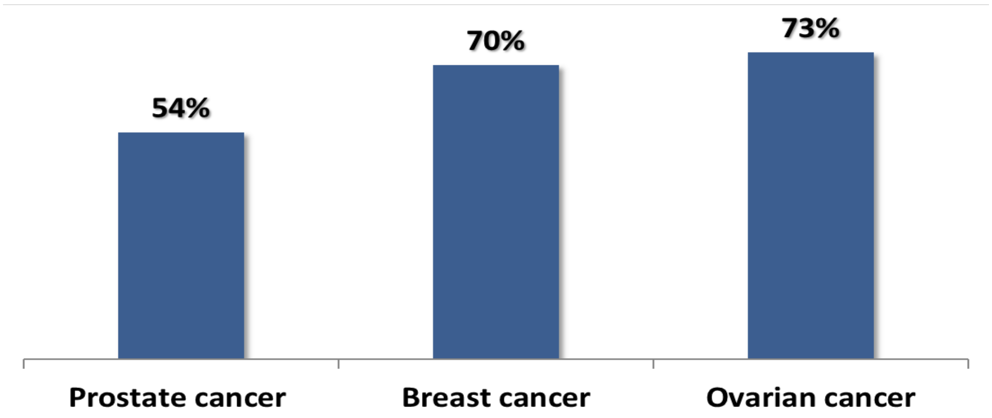


Figure 3. Top five most common reasons why patients felt they had had a positive experience with their first oncologist (n = 794)

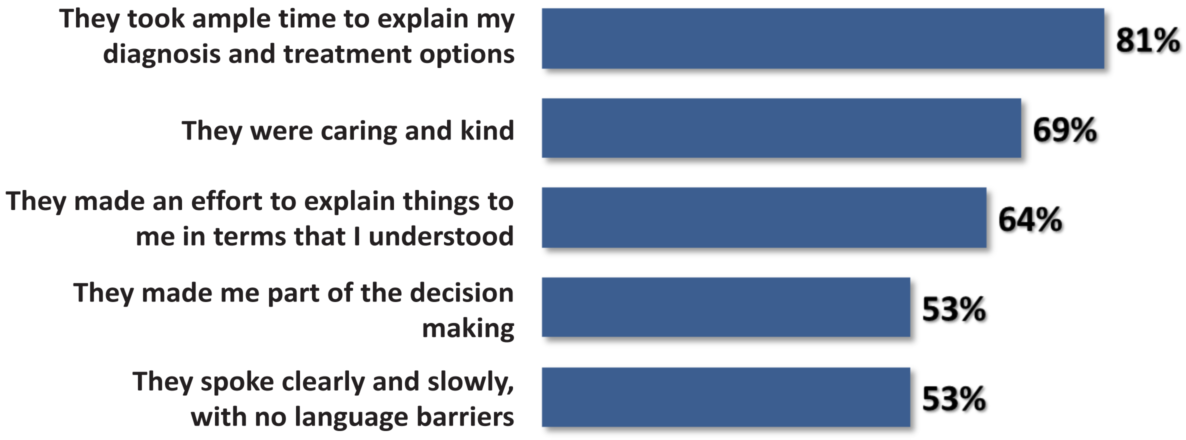
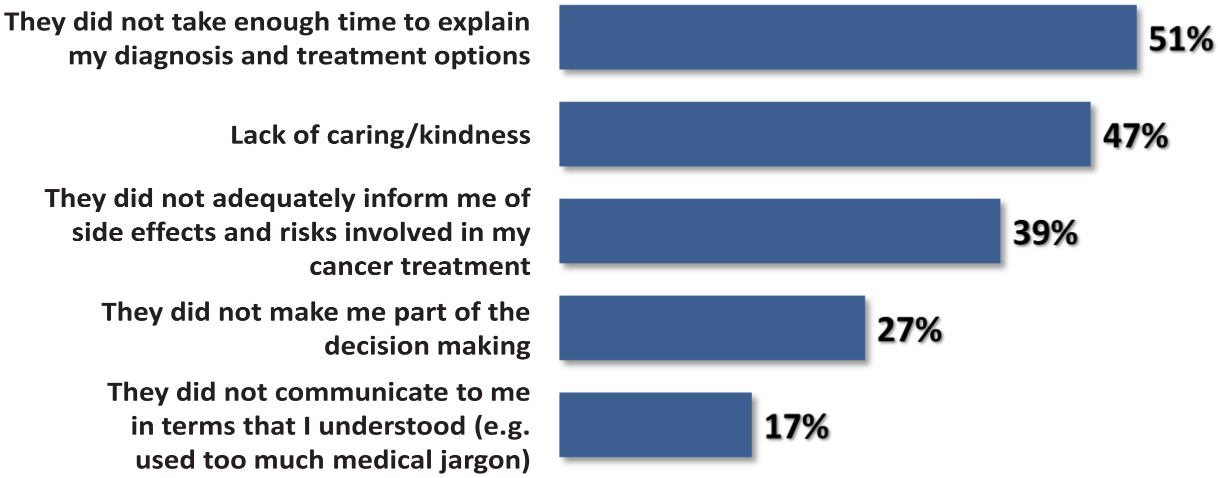


Figure 4. Top five most common reasons why patients felt they had had a negative experience with their first oncologist (n = 306)



On the flipside of the coin, a failure to communicate adequately with the patient appeared to underlie many negative experiences. Among patients who were extremely dissatisfied or dissatisfied with their first oncologist, the most commonly cited reason was that the oncologist 'did not take enough time to explain my diagnosis and treatment options' (51%) (Figure 4). A failure to communicate in clear, jargon-free language was also an important barrier, as was not being part of the decision-making process.

From a psychological perspective, a cancer patient can only gain from positive interaction with their doctor. Quality of life is a key metric when assessing the value of any cancer treatment strategy, and there is little doubt that constructive patient–physician relationships can have a positive impact on this.

To go one step further, this begs the question of whether being more satisfied with their oncologist interaction impacts on how well patients buy into and adhere to their treatment plan. There is a wealth of data to show that levels of adherence are linked with outcomes, including survival, in cancer. Any impact that high-quality patient–physician interaction and communication might have on adherence should be taken seriously as a driver of positive outcomes.

The age of the empowered patient

Cancer patients are increasingly taking control and are no longer passive recipients of the healthcare system. Instead, patients want to make active decisions about their treatment, and are sourcing their own information. They appreciate that vast amounts of material are now just a click of the mouse away and – unlike their oncologist – Dr Google does not require an appointment.

However, the quality of this information is highly variable and often unregulated. That presents a new challenge to the medical profession, and indeed to traditional

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information providers, such as patient organisations and drug manufacturers. The gap between oncologists and patients in the area of external information was evident from the survey results: fewer than half of patients (45%) said they were ‘always’ or ‘sometimes’ offered additional information resources (e.g. brochures, websites, support groups, etc.) during early interactions with their oncologist to help them deal with their diagnosis/treatment (Figure 5).

There was also substantial divergence in the degree to which oncologists were open to their patients looking for and discussing information sourced elsewhere (e.g. from the internet or patient groups). Almost half (43%) of patients in the survey said that their first oncologist was always or sometimes open to them looking for additional information elsewhere and to discussing it with them, but a further 25% said that their oncologist was rarely or never open to this (Figure 6). One respondent said that “*I would have appreciated more proactive discussion of the best sources of information about my cancer (beyond my doctor team and clinic). I am a voracious reader, and wanted to know where to go to get more detail.*”

Given that most patients are already sourcing information from elsewhere, oncologists should not be afraid to embrace this change. Quality remains a concern, but by encouraging their patients to seek outside information and discussing this material with them, oncologists can help to reinforce the value of ‘good information’ and nullify the impact of ‘bad information’. The end result will then be more knowledgeable and engaged patients.

In addition to the deluge on new information the internet has made available, a second key online

Figure 5. Frequency with which patients said they were offered additional information resources during their early interactions with their first oncologist (n = 1301)

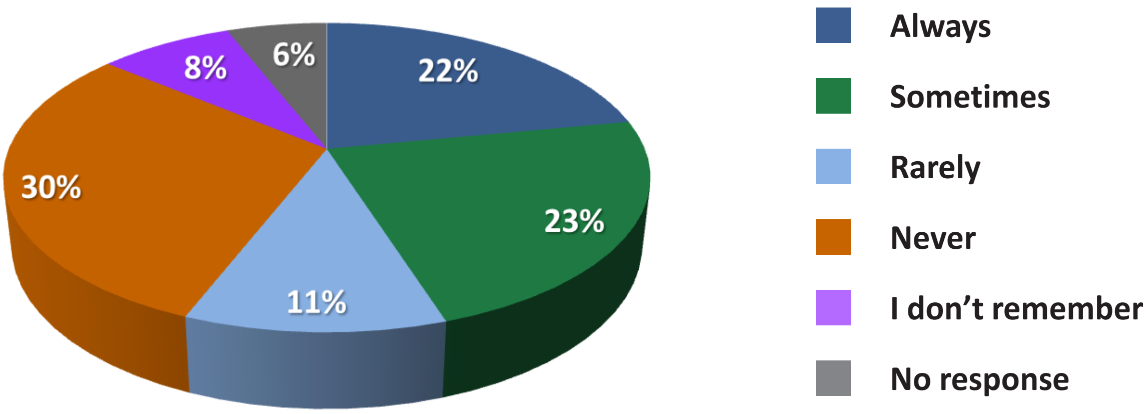
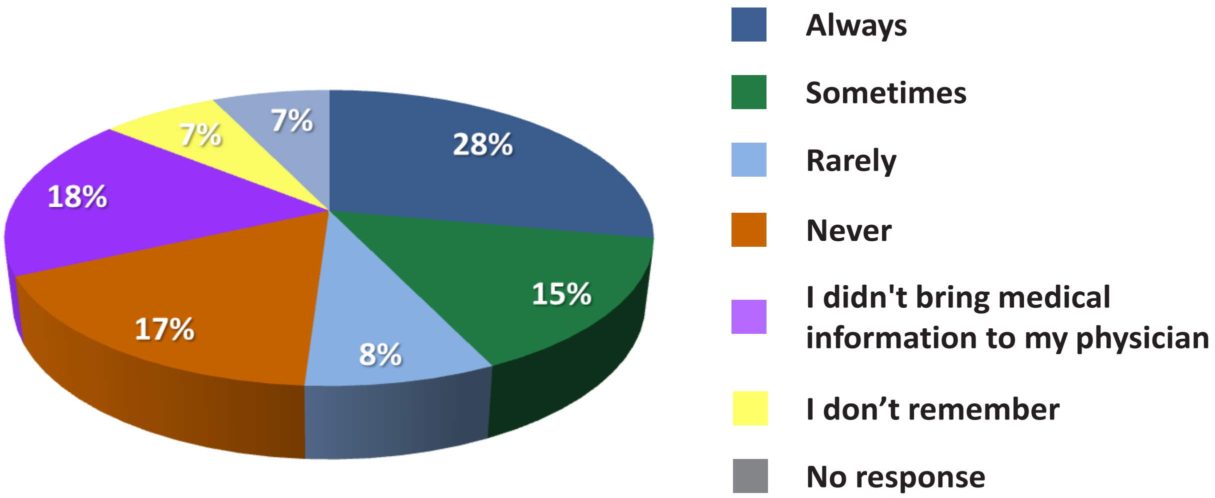


Figure 6. Frequency with which patients said their first oncologist was open to them looking for and discussing clinical information sourced elsewhere (n = 306)



phenomenon has been the advent of social media, which has made patient–patient interaction easier than it has ever been before. As a result, patients have many more opportunities to discuss their disease and their treatment plans, and to tell peers how they rate their own doctor. Furthermore, the modern patient is not only prepared to look elsewhere for information, they are also prepared to shop around for their healthcare provider.

Of those patients who said they were dissatisfied or extremely dissatisfied with their oncologist in Figure 1, more than half (54%) switched to a new oncologist, and a further 26% considered doing so (Figure 7). As one respondent put it, *“I had to go through four different doctors before I found one that had what I was looking for.”* The conclusion from this is clear: patients who are not happy with their oncologist are taking affirmative action and switching to a new one. As long as patients are realistic in their expectations of what a physician can and cannot provide, this is surely a positive development.

Ultimately, most patients want to be actively involved in the decision-making process around their care, and it is important for oncologists to explore this with them. As noted previously (Figure 3), more than half of patients felt that being involved in decision making was a key element of a positive interaction with their oncologist.

When asked specifically about their involvement in the selection of their cancer treatment, 56% of patients said that they had taken part in the process and had appreciated doing so; only 17% said that they had not, and wished they had been more involved (Figure 8). This suggests not only that the age of patient–physician joint decision making has well and truly arrived, but that the medical community is embracing it. Indeed, many patients now feel empowered to make their own decision, once their physician has laid out the options. According to one respondent: “*My oncologist was very knowledgeable. She made me very comfortable about my decision.*”

> *“[Healthcare providers] need to ensure that their interaction and communication with patients becomes ever more individualised”*

> *“Unlike their oncologist, Dr Google does not require an appointment.”*

However, it should be remembered that a small number of patients (3%) said that, although they were involved in treatment decision making, they would have preferred not to be. This highlights the importance of individualising the approach to specific patients, based on their own desire to be involved or not.

Communication lessons for personalised healthcare

Overall, some important themes emerge from this research:

- Cancer patients expect their doctor to interact and communicate with them in ways that are tailored to their own needs.
- Cancer patients expect to be part of the treatment decision-making process, and want to build a partnership of equals with their physician.
- Cancer patients have strong opinions about the doctors that treat them and are prepared to act on those judgements.
- The concept of ‘personalised healthcare’ in oncology needs to be engaged with the changing face of modern cancer patients if the success of novel therapies is to be maximised.

Oncology represents a complex and diverse disease area with sophisticated communications challenges, but there is no reason to believe that the lessons from this research cannot be carried beyond oncology and into other areas of medicine.

These findings feed into an important component of successful personalised healthcare delivery across the entire spectrum of medicine – effective patient communications by healthcare providers and by the pharma industry. Clearly, the scientific and medical components of personalised healthcare are essential, focusing as they do on the development and selection of more patient-appropriate therapies. However, to deliver truly personalised healthcare, both providers and the pharma industry must go further. They need to ensure that their interaction

Figure 7. Consideration of switching oncologist among patients with a negative experience with their first oncologist (n = 1301)

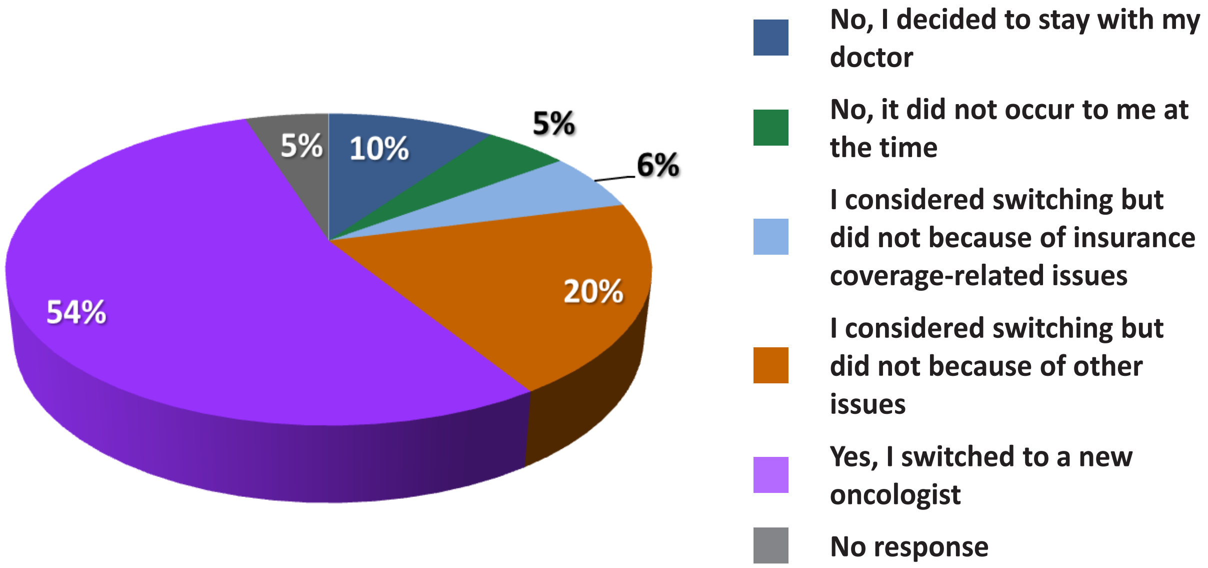
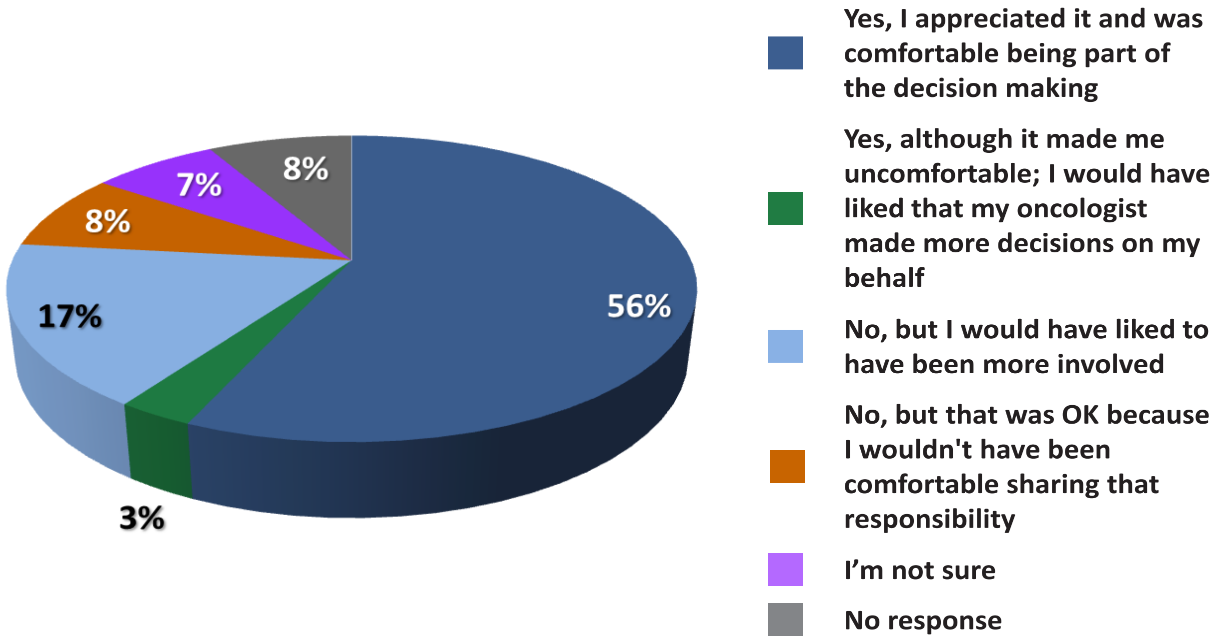


Figure 8. Patient perceptions of their involvement in the treatment decision making process (n = 1301)



and communication with patients becomes ever more individualised, leading ultimately to better treatment selection and improved outcomes for all.

In this regard, there is a clear analogy with good business practice in general, whether it is healthcare provision, shoe manufacturing or video-game production: yes, it is important to develop the best possible strategy and to personalise that strategy to your customer, but if you fail to engage the customer in a dialogue, you stand a greater chance of misinterpreting their needs and devising a strategy that simply doesn't work. Successful implementation requires everyone to be on board and to feel part of the process. This is as true for patients as it is for shoe buyers or video-gamers. The modern patient – whether in oncology or any other branch of medicine – is informed, educated and increasingly proactive about their treatment. There is a need to develop meaningful physician–patient partnerships. While oncologists are clearly doing a good job overall in this regard, physicians and the pharma industry must factor this into their understanding of 'personalised healthcare' and broader future activities.

In concluding this analysis, we recommend further research is conducted on a broader geographic basis, and across other disease areas, to understand the impact that the relationship between a patient and their healthcare provider (and associated stakeholders with whom they engage in disease management) has on the success of medical interventions. Through understanding such interaction, healthcare providers and the pharmaceutical industry can work collaboratively to improve patient outcomes.

About the authors

pharmaphorum media provides content and social media marketing and communications solutions for the pharmaceutical sector and also manages the industry leading channel, www.pharmaphorum.com, a digital podium for communicating thought leadership and innovation within pharma.

For more information visit **www.pharmaphorum.com**.

Inspire builds and manages peer-to-peer support communities for patients and caregivers, in partnership with leading patient advocacy organizations. Inspire helps life science organizations connect with patients. The analysis featured in this white paper was conducted via research with Inspire's cancer support communities, building upon a survey conducted jointly in December 2012 by Inspire and QuantiaMD, a US-based online physician community. Inspire is grateful to QuantiaMD for its contributions.

For more information, visit **http://corp.inspire.com**.

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