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“I just googled and read everything”: Exploring breast cancer survivors’ use of the internet to find information on complementary medicine

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Highlights

- All participants used the internet to find information on CAM.
- A diagnosis of cancer changes patients' needs.
- Use of the internet is connected to the self-management of cancer.
- Patients may not disclose their use of the internet to their healthcare team.

Abstract

Objective: Breast cancer survivors often turn to the internet as an information resource when deciding whether to use complementary and alternative medicine (CAM) but their use of online CAM-related resources is poorly understood. The objective was to explore breast cancer survivors' use of the internet when making decisions about CAM use.

Design: A purposive sample of 11 breast cancer survivors (mean age = 56) completed a quantitative questionnaire and a qualitative telephone interview. The theory of planned behaviour (TPB) was used to guide interview questions. Framework analysis and descriptive statistics were used.

Setting: United Kingdom.

Results: All participants found information on CAM using the internet and used some form of CAM after their diagnosis. Themes from the interviews went beyond the standard definitions of the TPB areas. Despite the lack of approval from their social network and healthcare team, participants used the internet to find information on CAM. Further, participants' cancer diagnosis changed their needs, transforming how they perceived and experienced the internet

Conclusions: Participants' use of the internet was more complex than can easily be explained by the TPB and was inherently connected to the experience of self-management for the consequences of cancer and its treatment. As breast cancer survivors may not disclose their use of the internet to their healthcare team, healthcare professionals need to be aware that the information available on the internet plays a factor in the decision-making process to use CAM.

Keywords: Complementary therapies; Breast cancer; Self-management; Decision making; Information seeking behaviour; Internet

1. Introduction

There are approximately two million people living with or beyond cancer in the UK,¹ these individuals are described as 'cancer survivors'.² Breast cancer is currently the most commonly diagnosed cancer in the UK; approximately 49,900 women and 350 men were diagnosed with breast cancer in the UK in 2011.³ Throughout the disease trajectory breast cancer survivors can experience a range of physical and psychological problems such as anxiety, breathlessness, depression, fatigue, lymphedema, nausea, pain and stress; these effects may also develop into long-term issues.^{4; 5; 6; 7; 8}

As a way of living with the effects of cancer, cancer survivors may use a range of self-management techniques. Self-management is any activity and behaviour undertaken by individuals to control their health and deal with disease.⁹ Self-management is now an embedded component of care for cancer survivors; the National Cancer Survivorship Initiative supported the development of a care pathway called the 'recovery package' which includes providing information and support to individuals to manage the consequences of cancer.² In the UK, NHS Improvement and the Department of Health worked together with the National Cancer Survivorship Initiative to provide resources and support to encourage self-management activity amongst cancer survivors.^{10; 11} Research indicates that many cancer survivors already use a wide range of resources to self-manage the problems associated with cancer, such as visiting healthcare professionals and services, support networks, and using the internet for information.¹²

The literature suggests that many cancer survivors also use Complementary and Alternative Medicine (CAM) as a form of self-management. CAM can be defined as: 'a group of diverse medical health care systems, practices, and products that are not generally considered to be part of conventional medicine'.¹³ The National Institute for Clinical Excellence (2004) suggest that CAM therapies are being used by up to one third of patients with cancer. Cancer survivors' motivation for using CAM includes: increasing treatment options, reducing the side-effects of conventional treatment, coping with the psychological impact of cancer, and dissatisfaction with conventional medicine.^{14; 15; 16; 17}

A review of self-management activities by people affected by cancer found that using the internet to find information was common among women with breast cancer.¹⁵ One of the topics commonly searched for on the internet is CAM; a questionnaire evaluating internet use by breast cancer patients found that 37% of participants used the internet to seek information on CAM.¹⁸ Evidence suggests that women use the internet particularly to gather and evaluate information on CAM in the initial stages of deciding whether to use CAM.^{19; 20; 21} However, there is little evidence-based, officially-sanctioned guidance on CAM for cancer survivors, despite recommendations that supportive resources are provided for any form of self-management.^{12; 22} CAM information that is available to cancer survivors online has been heavily criticised: patients using such information may be misinformed and unknowingly taking risks with their health.^{23; 24}

There is currently little research exploring the relationship between cancer survivors' internet use and their decision-making processes for CAM use. Therefore, this qualitative study aimed to explore how breast cancer survivors use the internet to inform decisions about CAM use. The research objectives were to: examine the barriers and facilitators to using the internet as a self-management resource, and explore the experiences of breast cancer survivors in using the internet to make decisions on CAM treatment.

The theory of planned behaviour (TPB) was used as a guiding framework. The TPB is an established model of the psychological predictors associated with intentional human actions (see Fig. 1).^{25 ; 26} Within this research context, the TPB suggests that the following factors influence breast cancer survivors' intention to get information on CAM via the internet: a) a positive attitude towards using the internet, b) the view that using the internet for this purpose is a normal behaviour, and c) a belief that they have the ability and resources to use the internet for this purpose. Ultimately, a better understanding of how and why women use the internet when making decisions about CAM use could inform the future development of web-based resources to support informed decision-making.¹⁹

2. Methods

2.1. Participants

The inclusion criteria were: breast cancer survivors who were 18 years of age or older who had completed active cancer treatment (chemotherapy, radiotherapy and/or surgery) in the last five years, were internet users and had considered using some form of CAM. Participants who were taking long-term oral chemotherapy or hormone therapy were also eligible. The study was advertised in regional newspapers, on the Macmillan Cancer Support Cancer Voices Network and posters were put up locally around the community. There was no previous relationship between the research team and participants. Written informed consent was taken from each participant. The study protocol was approved by the University Ethics and Research Governance Committee (Ethics no: 11093). Fifteen individuals registered an interest in the study, participants were recruited until data saturation was reached.²⁷

2.2. Data collection

A mixed-method design was used, combining a qualitative interview study with an embedded questionnaire study.²⁸ Interviews were chosen as they allow for participants to express themselves, giving individuals a chance to tell the story of their experiences.^{29; 30 ; 31}

The qualitative study was the main focus and aimed to explore participants' experiences of using the internet to make decisions about CAM and identify the barriers and facilitators to using the internet as a self-management resource. Eight open-ended questions and probes were developed in an interview schedule to aid the interviewer to explore participants' attitudes and behaviours towards using the internet to find information about CAM. All participants were asked an initial opening question "Can you tell me all about your experiences of finding out about complementary and alternative therapies?", giving participants a chance to tell the story of their experiences, other topics covered in the interview schedule are shown in Table 1. Interviews were completed over the telephone using a semi-structured topic guide, developed using the TPB.²⁵ ; 32 Interviews lasted on average 40 min long. The interviews were completed by MH, a female masters student, with previous training in conducting qualitative interviews. The questionnaire contained 4 questions about participants' cancer diagnosis, 6 questions about participants' internet use (covering access to the internet and satisfaction with IT skills), and 1 question regarding current or previous use of CAM therapies.

2.3. Data analysis

Interviews were audio recorded and transcribed verbatim by the interviewer, before being imported into the computer-assisted qualitative data analysis software NVivo (version 10) for analysis.³³ Framework analysis was used as it provides a pragmatic and systematic approach to analysing data that is well-suited to theoretically-guided projects as it allows for both a deductive and inductive approach to analysis.^{34; 35; 36 ; 37}

The first three interviews were coded using line-by-line open coding, taking an inductive approach to coding, with code names derived directly from interpreting the data. Codes were refined, descriptions developed and grouped into higher-level categories enabling an in-depth inductive analysis to capture all elements and concepts within the data. The initial coding was conducted by one author, with refinement and grouping into higher-level categories by two authors. Using a deductive approach, categories were then placed under themes relating to the TPB where relevant. This approach allowed for data and categories out of the scope of the TPB to be included in the analysis. Tables were generated to synthesise and depict relationships within the data. The remainder of interviews were coded deductively using the framework, but with a somewhat inductive approach, allowing for new code development if appropriate.

The questionnaire data were analysed descriptively using SPSS (version 21).³⁸ The qualitative and quantitative data was combined during analysis; the questionnaire provided complementary data to the interviews post qualitative data analysis, presenting a more complete picture of the possible influences over participants' behaviour.^{28 ; 39} Findings were compared to identify agreement and inconsistencies within the results.³⁹ Quotes were selected to best describe the inductive categories and TPB-related themes, as well as those depicting conflicting views. Pseudonyms were given to participants but additional details such as age have not been provided as this was deemed irrelevant

to descriptions of their behaviour. The study has been written up according to the consolidated criteria for reporting qualitative studies (COREQ).⁴⁰

3. Results

3.1. Participant characteristics

Out of 16 individuals who registered interest in participating in the study, 11 (69%) participated in the study; 4 decided not to participate and 1 was ineligible. Table 2 displays the demographic and clinical characteristics of the 11 participants. All participants were female, aged between 45 and 67 (mean = 56). Treatment plans varied: 90.9% had radiotherapy, 81.8% had surgery, 63.6% received chemotherapy, 54.5% hormone therapy and 36.4% targeted therapies. Some participants received more than one treatment; one participant had refused all conventional biomedical treatment. Four participants were still receiving long-term hormonal treatments.

3.2. Themes

The TPB suggests that the following factors influence breast cancer survivors' intention to get information on CAM via the internet: a) a positive attitude towards using the internet, b) the view that using the internet for this purpose is a normal behaviour, and c) a belief that they have the ability and resources to use the internet for this purpose. However, this study found that participants' use of the internet to find information on CAM cannot easily be explained by the TPB.

3.3. Use of the internet and CAM

All participants were familiar with using the internet and used it daily (see Table 3); some relied heavily on the internet for everyday activities. All participants had received information about CAM from the internet after their diagnosis and were currently using or had used some form of CAM in the past. The number of CAM therapies used by participants ranged from 1 to 18 therapies (mean = 9). The most commonly used therapy was massage, followed by acupuncture and the use of vitamins and minerals (see Table 4).

Some participants discussed using CAM before their cancer diagnosis and had been introduced to CAM through their social network. Experiences of using various therapies before cancer encouraged use of CAM after their diagnosis. Participants viewed CAM as beneficial and spoke positively about the idea of CAM in addition to the individual therapies they received. "I think I'm open to complementary medicines anyway. I believe they should be available on the NHS" (Ginny).

3.4. Intentional and incidental search for CAM information

All participants intended to use the internet to find information. However, the specific information they intended to search for varied. Many participants intended to use the internet to seek self-

management advice to deal with cancer, the treatment and side-effects, and whilst using the internet in this way they happened to find information on CAM. "I just wanted to be able to put my health in the best position that I possibly could and you know that meant exploring all avenues" (Eleanor).

Others intended to use the internet to get information specifically about CAM, and how it could be used to combat the side-effects of cancer and its treatment as well as to help them cope emotionally with their diagnosis. Some participants also aimed to find CAM practitioners and therapy centres online. "So when I was diagnosed with breast cancer, I wasn't really using any at that time although I had previously. So, that was what immediately came to my mind, that I should use some complementary therapies" (Claire).

3.5. Complex needs change attitudes towards using the internet to find information on CAM

Many participants expressed a need for information after their cancer diagnosis and viewed the internet as the only accessible way to get information. "So yes of course I googled it, because they weren't really giving me another information, so I wanted to find out well okay what am I dealing with here" (Harriet). They depicted receiving a limited time with healthcare professionals and had a considerable lack of information elsewhere.

Participants spoke very positively of using the internet, pleased with the large amounts of information readily available. The internet was depicted as having many advantages, being a practical and convenient way to access relevant information. "You can do it whenever you want to do it. You can do it in the middle of the night if you can't sleep. You can take your time, you are in your own comfort of home so, I don't feel embarrassed looking at it." (Josephine).

Participants also acknowledged certain disadvantages to using the internet for the purpose of finding information on CAM. Due to the unrestricted nature of the internet, many had concerns about the legitimacy of website content: "I probably had to do quite a lot of the work myself to find what I thought were the right websites" (Diane). The vulnerability of having a cancer diagnosis was present in the participants' views, acknowledging that information on the internet could impact them negatively. They felt that people diagnosed with cancer might be susceptible to believing unwarranted claims due to the emotional nature of a cancer diagnosis. "And when people are desperate, sometimes you believe what you want to believe. Because that's better than what people are telling you" (Ginny).

Although none of the participants spoke of becoming upset by online information, many recognised this may be an issue for others in a similar situation. "The other disadvantage I suppose is that you

can start reading things that make you fear the worst things that are actually happening to you” (Claire).

The participants’ cancer diagnosis seemed to transform how they experienced the internet. Due to their cancer diagnosis, they had a need for information that they perceived they could not access elsewhere. Whilst participants discussed both advantages and disadvantages to using the internet to find information about CAM, the behaviour was perceived as more complex than “good” or “bad”. Their perceptions of the behaviour changed to one of necessity due to their need for information as cancer survivors.

3.6. Social context: beyond subjective norms

Although all participants had used some form of CAM after their diagnosis, the majority of participants felt their healthcare professionals were unsupportive or uninterested in their use of CAM. “When I spoke to the oncologist about alternative treatments she just... they just said ‘no, don’t use anything other than what we tell you’. They just weren’t interested” (Isobel). Whilst many participants expressed they would like their healthcare team to be more supportive of their choice to use CAM and to even encourage CAM use during cancer, participants stated they would have chosen to use CAM without approval from their GP, oncologist or breast cancer nurse. “Whether they said no or yes I would have still done it. I would have totally ignored them” (Anne).

Participants were divided over discussing the information they had read online with healthcare professionals. As many felt that their healthcare team were unsupportive of CAM this led them to pursue this avenue on their own. Although some participants did discuss the information they found online they felt these discussions were severely restricted by the limited time available with their healthcare team.

A few participants knew of other people within their social network who also used the internet to find other information about CAM online. However, most participants knew other people used the internet for this purpose through the connections they had made on the internet. Online forums were seen as a way to receive both information in the form of personal experiences but also as a form of support “And it’s all to do with, that I’m not on my own, cos there’s lots of other people, you know, that are going through it as well” (Isobel).

Although participants knew other people who used the internet to find information, they had received mixed approval of the behaviour. “But I just remember at the beginning, people said ‘don’t go googling stuff because you know, you’ll get a fright’” (Harriet). Despite the lack of approval from their social network and healthcare team, participants rejected the social norms related to the behaviour and concluded that they would use the internet for this purpose. “I mean some of the

nurses did say it's not a very good idea but I thought 'no, it's up to me, it's my body, what information I find out about it'" (Anne).

3.7. It's easy if you know how: perceptions of ability to use the internet to find CAM information

All the participants described using the internet to find information on CAM as being an easy process. However, participants did acknowledge that their IT skills and routine use of the internet played a role in finding the task straightforward and simple. This was also depicted through the questionnaires; 8 participants (72.7%) were very confident and the 3 remaining participants (27.3%) only somewhat confident in using computers and the internet. 54.5% of participants were very satisfied with their current skills for using the internet and 36.4% somewhat satisfied. Although not all participants were very confident in using computers and some were only somewhat satisfied with their internet skills, in the qualitative interviews all participants expressed how easy it was to use the internet.

Although participants found the process uncomplicated and unproblematic, they acknowledged a need for certain external resources. Many felt that all that was needed was basic IT equipment, which could be a computer, laptop, tablet or even a phone. Some explored this further, stating that individuals would also require internet access and substantial finances.

A few participants discussed how the physical and psychological symptoms associated with cancer and treatment could limit individuals from accessing the internet and being able to comprehend the information available online. "I think people who are quite ill, it's probably more difficult for them. And possibly quite difficult to concentrate" (Claire).

In addition to external resources, participants also suggested there was a need for several internal skills in order to be able to use the internet effectively to find information about CAM. Basic IT skills and confidence was described as a necessity. Literacy was also discussed as a required skill to comprehend the information available "I think they might be quite difficult for people to understand who aren't familiar with some of the language that's used. I don't particularly mean jargon but I just mean the way it's written" (Ginny).

Exploring the skills required to be able to find CAM information online led to thoughts over whether skills were associated with age. Some participants felt that older family members were also familiar with the internet and would be able to complete the task. However, others felt that "the older generation" may not have the knowledge or skills to be able to use the internet, but this would change through new generations. Views surrounding the older generation's ability to perform this behaviour was linked to personal experiences within their own families and social networks.

3.8. Behaviour: searching for CAM information online

All participants had read information about CAM on the internet whether their intention was to search for self-management information or to seek information specifically on CAM. "I just spent every single hour during the day, during the evening up until say 1am or 2am in the morning, going to bed, getting up, back on the internet, just really reading everything I could" (Eleanor).

Participants discussed the different websites and techniques they used to find information. When searching for information, participants varied in the type of information they wanted; most participants wanted to read evidence and research about CAM therapies before they used them but others wanted to read personal experiences from other people with a cancer diagnosis. However, all information found online was appreciated during the time of a cancer diagnosis. "I think all the information is valuable and all intelligence is valuable and the internet shares that, so even somebody's opinion is worthy of knowing about" (Eleanor).

Most participants used methods of judging the legitimacy of website content before continuing with the recommendations on CAM. Many participants stuck to websites that they believed were trustworthy websites, such as those provided by Macmillan Cancer Support and Cancer Research UK. For participants to feel confident with the recommendations on websites, they would use multiple sources to validate the information, with some participants judging content against their previous experiences of CAM. "I would look at more than one website, so I'd look at multiple websites just to check that everyone is saying the same thing" (Diane). Participants were especially wary of outlandish claims and information provided by companies or individuals selling products; participants also expressed concerns over finding a practitioner online.

Despite the internet being the main source of information on CAM for participants, all but two participants felt that other means were available to them to access information. However, some participants expressed that information from other resources was not as detailed or helpful as the information found online.

4. Discussion

This mixed-method study suggests that using the internet within the decision-making process is a complex behaviour for cancer survivors. Contrary to the underlying principles of the TPB, participants' intention to use the internet was only partially fuelled by their attitudes towards the internet, the subjective norms over using the internet and how they perceived their control over using the internet.

In the decision making process to use CAM, participants looked for information online on self-management or CAM. Previous research on cancer survivors' use of the internet has shown that these are two distinct topics when seeking information.^{18; 41; 42; 43 ; 44} The act of searching information was not always a deliberate behaviour to find information on CAM. Instead, it often occurred within the context of finding general self-management information for the effects of cancer. Previous literature depicts searching for information specifically about CAM as part of the decision-making process rather than a general search for self-management information to cope with cancer, deal with side-effects and increase treatment options.^{19 ; 20}

Participants shared the view that the internet was the only way to get information to help them make their decision on whether to use CAM. This challenges previous research in the area suggesting the internet is a low priority source of information, with cancer survivors preferring recommendations from their social network and healthcare providers.^{19; 20 ; 45} Participants expressed their main source of information was the internet, acknowledging this was possible because of their IT skills and access to IT resources and without these factors it may be difficult to acquire the required information, in line with previous research.^{42; 46 ; 47}

Participants used the internet despite this not always being perceived as socially approved. Although participants did know other cancer survivors who used the internet for this purpose, they felt unsupported by healthcare professionals and within their social network about their use of the internet. This finding differs from participants' influences to use CAM, as use of CAM within their social network was deemed important in the decision to use CAM but not to find information online. Healthcare professionals and policy makers need to acknowledge the lack of discussions around these behaviours and the impact this may have on cancer survivors' empowerment to conduct self-management activities.^{10; 11; 19 ; 21}

Literature on the decision-making process has described how cancer survivors gather and evaluate information on CAM.^{19 ; 21} Participants in our study preferred to access information through research findings and reading people's experiences online; in line with previous research.^{18; 42 ; 44} In accordance with other literature, participants were wary of the source validity of information and the quality of content and used various techniques to judge the quality of information available.^{19; 21 ; 48} This information seeking and evaluating behaviour is an essential component in self-management.²⁴ and the ability to assess websites in the decision-making process needs to be respected by clinicians. In guidance provided by the National Cancer Survivorship Initiative (2013) it is believed the majority of cancer survivors should be able to self-manage the consequences of cancer and its treatment, but currently self-management is driven by healthcare professionals through programmes such as the recovery package.² Healthcare professionals may lack the skills in identifying and supporting cancer survivors who want to self-manage the consequences of cancer and its treatment; this could be a constructive challenge for current health professional-led self-management models.

This study has a number of limitations. The majority of participants felt positively about CAM and so the findings do not capture the behaviour and beliefs of breast cancer survivors who have negative attitudes towards CAM. Although the study sample may seem relatively young, 80% of breast cancer diagnoses are in women over 50, providing an initial exploration into patients' experiences.³

5. Conclusion

This study provides insight into the role of the internet in cancer survivors' decision-making process to use CAM. Participants' use of the internet to find information on CAM cannot easily be explained by the TPB; our findings suggest the theory may provide a limited understanding of the complex behaviours associated with illnesses that have complicated disease trajectories such as cancer. Results indicate that the information available on the internet plays a factor in the decision-making process to use CAM, as it may be seen as the only comprehensive way to get information on CAM. Healthcare professionals must acknowledge the limited time they have with patients and the need patients have for information; if clinicians feel they cannot provide this information more focus needs to be placed on improving access to information online. Although this study provides a better understanding into how breast cancer survivors make judgements over the legitimacy of website content, the results deliver a persuasive argument for the development of a website with evidence-based resources to improve the quality of CAM information for patients and support their self-management decisions.

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Table 1.

Topics covered in interviews

Theory of Planned Behaviour	Topics covered by interview schedule and prompts
Attitudes	Advantages of using the internet to find information on CAM, disadvantages of using the internet to find information on CAM
Subjective Norms	Other people's thoughts on the behaviour, views of healthcare professionals, views of family and friends, other people use of the internet for this purpose
Perceived Behavioural Control	Confidence in using the internet, confidence in using computers, skills needed to be able to find information effectively, reasons or situations it might be difficult to use the internet
Intention	Informational needs, interests in CAM,
Behaviour	Experiences of using the internet, other sources of information, availability of information, type and style of information

Table 2. Characteristics of study population (n = 11).

Characteristic	n	%^a
<i>Gender</i>		
Female	11	100
<i>Age</i>		
45–49	2	18
50–54	3	27
55–59	3	27
60–64	2	18
65–69	1	9
<i>Ethnicity</i>		
White	10	91
Chose to not respond	1	9
<i>Cancer Diagnosis</i>		
Ductal Carcinoma in Situ	5	17
Lobular Carcinoma in Situ	1	3
Invasive Ductal Carcinoma	5	17
Lymph Node Involvement	3	10
Estrogen Receptor Positive (ER+)	6	21
Progesterone Receptor Positive (PR+)	2	7
Human Epidermal Growth Factor Positive (HER2+)	3	10
Human Epidermal Growth Factor Negative (HER2–)	1	3
BRAC1 Gene Mutation	1	3
BRAC2 Gene Mutation	2	7
<i>Age of Diagnosis</i>		
40–44	4	36
45–49	1	9
50–54	3	27
55–59	1	9
60–64	1	9
Chose to not respond	1	9
<i>Time since end of active cancer treatment</i>		
6 months–1 year	1	9
1 year–2 years	2	18
2 years–3 years	1	9
3 years–4 years	3	27
4 years–5 years	1	9
5 years+	1	9
Not applicable	2	9

a Given to the nearest whole number.

Table 3.

Participants use of the Internet.

	n	% ^a
<i>Length of internet use</i>		
More than 3 years up to 6 years	1	9
More than 6 years	10	91
<i>Frequency of internet use</i>		
Daily	11	100
<i>Place of access to the internet</i>		
Home	11	100
Work	4	36

a Given to the nearest whole number.

Table 4.

Participants use of CAM therapies.

CAM Therapies	n %^a
Acupressure	2 18
Acupuncture	7 64
Aromatherapy	6 55
Art Therapy	4 36
Ayurveda	2 18
Bach Flower Remedy	3 27
Chiropractic	1 9
Dance Movement Therapy	3 27
Herbal Medicine	2 18
Homeopathy	6 55
Hypnosis	3 27
Massage	9 82
Meditation	5 46
Music Therapy	3 27
Osteopathy	1 9
Other	6 55
Reflexology	5 46
Reiki	4 36
Relaxation/Breathing Technique	6 55
Shiatsu	1 9
Spiritual Healing	5 46
Traditional Chinese Medicine	1 9
Visualization	6 55
Vitamins and Minerals	7 64
Yoga	6 55

a Given to the nearest whole number.

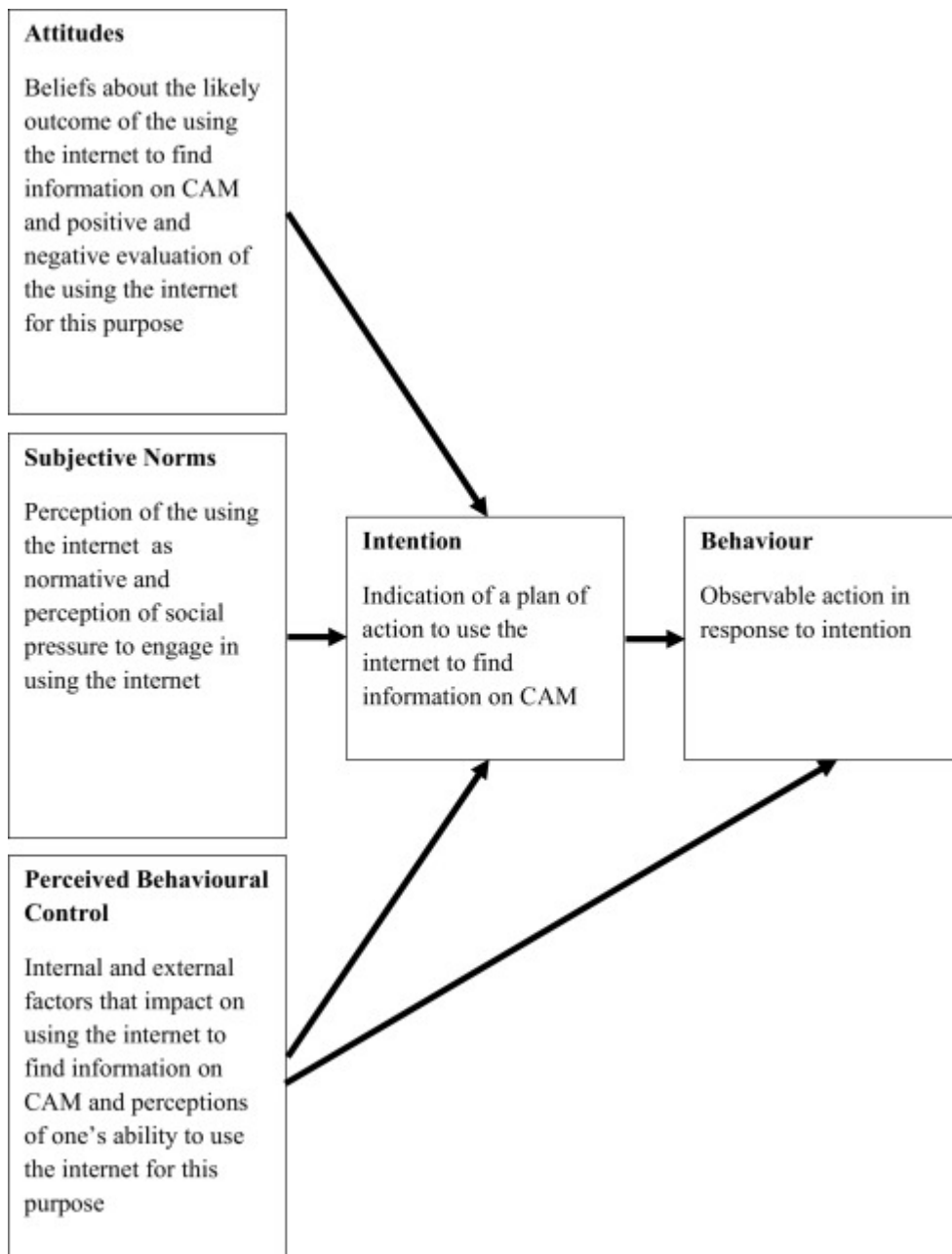


Figure 1. The theory of planned behaviour.