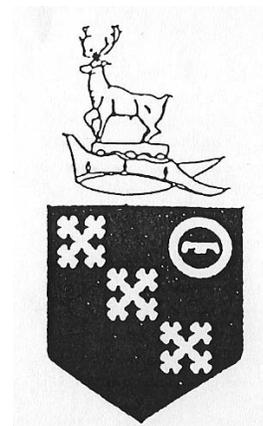




Evaluation of the Knowledge and Information Centre at St Thomas' Hospital: Final Report

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The Cicely Northcote Trust

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Executive summary

Introduction

Patient involvement in health care is now a priority for the NHS. Indeed patients are seen as partners in the health care process. Initiatives such as the Expert Patients Programme promote self-management and empowerment through engagement with other health care users and professionals.

Patients are encouraged to learn more about their health and take responsibility for their wellbeing. This requires patients to be able to access and understand reliable health information. However this can be unclear and information from health professionals can often be incomplete or complex.

The Knowledge and Information Centre (KIC) at St Thomas' Hospital aims to provide patients, staff and visitors with information on health conditions. It operates as a comprehensive resource centre, offering Trust-wide access to a wide range of health related books and leaflets, internet and email facilities, details of local and national support groups and information on drop-in clinics. Patients and visitors are able to find information for themselves, relax and read a newspaper or obtain assistance from staff to find more complex information. The KIC can be seen as a bridge between the professional clinicians and patients. The KIC is one of only a few such services in the country and as such this evaluation will provide evidence on whether this service positively contributes to patient involvement in the NHS.

Aims

This study aimed to evaluate both the experience of using the KIC service and the impact obtaining information has on users and their ability to manage their health.

Methods

The evaluation focused on the KIC clients for whom a detailed assessment of their information needs was made by the KIC staff (i.e., those people who made use of the complex enquiry service).

The evaluation used quantitative and qualitative approaches. There were three stages to the evaluation:

1. Every client who used the complex enquiry service was asked to complete a baseline/ experience questionnaire when they used the KIC service. 130 questionnaires were distributed and 61 were returned completed. On this first questionnaire clients were asked to indicate if they would be willing to take part in the second and third stages of the project.
2. Clients who agreed to participate in stage 2 completed a follow-up/ impact questionnaire one month after their baseline/ experience questionnaire. 36 questionnaires were returned at this stage.
3. Clients who agreed to participate in the final stage participated in a semi-

structured interview with the researcher. 18 people took part in interviews.

Questionnaires were analysed using frequencies and basic statistics. Interviews were analysed by theme.

Ethical and research governance approvals were secured from Guy's Research Ethics Committee, London South Bank University, Faculty of Health and Social Care Research Ethics Committee and Guy's R&D Department. The project was overseen by a Steering Group.

Our participants

The majority of people who completed a baseline/ experience questionnaire were female (66%), aged between 25 and 64 years (74%) and were white (72%). The majority had English as their first language (86%) and were either patients (46%) or visitors (21%) at St Thomas' Hospital.

The majority of people who completed follow-up/ impact questionnaire were female (75%), aged between 25 and 64 years (72%) and were white (72%). Ninety-two percent used English as their first language and 33% were patients at St Thomas' Hospital and 31% were visitors.

Of the people who participated in interviews 72% were female, 72% were aged between 25 and 64 years and 78% were white. All interviewees used English as their first language and 61% were either visitors or patients at St Thomas' Hospital.

Experience findings

The findings that relate to people's experiences of the KIC are briefly noted below:

Finding and accessing the KIC

- The majority of people came across KIC in passing, although some were also referred by health professionals.
- First impressions of the KIC were very positive. However some people were unsure what the KIC was and likened it to a library.
- The KIC was seen as being accessible for those with physical disabilities, although some were concerned that it would not be accessible for those with poor English skills as they may require a translator/ interpreter.

The KIC environment

- The KIC was viewed as spacious, quiet and peaceful. People enjoyed coming to the KIC and felt that the KIC provided a warm and welcoming atmosphere.

Using the KIC

- The majority of people in our study used the KIC to find out about

health conditions.

- The majority of people said they found it easy to find information on their own at the KIC. However some people needed help from staff, mainly because they could not use computers.

The KIC staff

- People were generally impressed by the KIC staff and felt they provided an excellent service. They felt that the staff communicated the difference between health information and health advice, respected their privacy and were easy to approach for help.
- The information provided by staff was sufficient in depth and quality and was delivered quickly. Staff often went out of their way to find additional information.
- People felt that staff communicated in a sensitive manner and were compassionate.

The value of the KIC

- The KIC was seen as overwhelmingly useful and an asset to St Thomas' Hospital.

Impact findings

The findings that show how using the KIC impacted on peoples' lives are briefly described below:

- An increased understanding of a health issue was the biggest benefit of using the KIC.
- Information provided helped people come to terms with their health issue. However sometimes it could be frightening at first as it brought home the reality of the situation.
- Using the KIC helped people gain confidence when dealing with health professionals and making decisions about their health care.
- Having clear, authoritative information legitimised people's health issues and empowered them. It also motivated them to find out more information.
- People sometimes passed information from the KIC onto others so the impact was not just restricted to those who directly accessed the service.
- Using the KIC also had social benefits such as making people feel less isolated and lonely and helping them meet new people or stay in touch with friends or family via email.

Suggestions for improvements

The main suggestions made by participants related to the structure or organisation of the KIC and are briefly listed below. Some people would like to see the following:

Physical environment

- A chair by the kiosk outside the KIC.
- A separate TV room so that people can properly watch TV if they wanted to.

Organisation of service

- An increase in the range of health conditions on which KIC provides information and more material on health conditions.
- Longer opening hours to allow those that work a traditional 9am – 5pm week to access the KIC.
- An outreach service with staff visiting wards to help people access health information.
- Better publicity and signage to the KIC.
- An expansion of the benefits service or a telephone service which you could call up to access health information.
- A training function at the KIC to teach people how to use computers if they are unable to do so.
- More volunteers.
- Someone independent who can talk with clients in more depth about the health information or provide health advice.
- KIC working with clinicians to produce better patient information for people using St Thomas' Hospital.
- Expansion of the KIC service to other sites.

Conclusions

The KIC service is viewed positively by users of the complex enquiry service. It is valued most for its staff and the information that they are able to provide. The information is valuable in that it helps improve knowledge or awareness about a health condition and also increases the confidence of clients to liaise with health professionals. Overall, it contributes positively patients' experience of St Thomas' Hospital. Clients would like to see the KIC expand to other sites.

Recommendations and further actions

A number of recommendations are made through the evaluation. The main recommendations are listed below. In the full report all recommendations and responses to these from the KIC management team can also be viewed:

- Extend open hours to increase access.
- Provide a private space for individuals to raise issues confidentially.
- Develop a publicity strategy for the KIC that signposts to the KIC service and highlights the range of material available.
- Increase the number of volunteers and signpost clients onto other health advocates where necessary.
- Check all information provided to clients is at a level that they can understand.
- Elicit suggestions from clients around material they would like to see

- added to the KIC.
- Encourage clients to discuss health information with their healthcare professionals.
 - Offer clients information on further sources of support when information is provided.
 - Work more closely with other departments within St Thomas' in relation to identifying and producing patient information materials.
 - Consider offering an outreach service to wards for St Thomas' patients' who are not able to come to the KIC.
 - Consider providing training for clients around health information.

Section 1: Introduction

1.1 Patient involvement in health care

In the past the medical field has been a domain of experts, often to the exclusion of patients. However the NHS modernisation agenda sets out to challenge this and to actively involve patients in healthcare and decision making (DH, 2000).

Key reasons for this shift towards patient involvement can be seen in changes to the burden of disease in the UK. Long term conditions presently affect 15.4 million people in England (DH, 2004a; 2008) and this number is rising. Common long term conditions include diabetes, heart disease, asthma, chronic obstructive pulmonary disease (COPD), mental illness, arthritis and neurological disorders such as multiple sclerosis, epilepsy and Parkinson's disease. Such conditions cannot be currently cured but rather only controlled with medication or other therapies (DH, 2004a; 2008).

The rise in long term conditions can be attributed to several issues. Firstly, the UK has an ageing population due to declining birth and mortality rates (NSO, 2008). Our older population is forecast to continue to grow with a 50% increase of people aged 65 – 84 and a 100% increase of people aged 85 and above by 2031 (GAD cited in Green & Miles, 2007). The issue of the ageing population is important because older people are more likely to suffer from a long term condition (DH, 2001). Secondly, just a few risk factors account for the majority of global disease burden. For example, high blood pressure, high cholesterol, alcohol and tobacco use and obesity link are major causes of cardiovascular disease which account globally for 17 million deaths per year (WHO, 2008). This indicates that lifestyle choices are playing an important part in the burden of long term conditions.

The cost of treating and managing long term conditions is vast. A recent estimate suggests that this accounts for 69% of total health and social care spending in England (DH, 2008). With an acute illness patients may be relatively passive, whereas long term conditions offer increased opportunities for patients to become co-partners with health professionals. However to become more actively involved in their own healthcare patients need to be able to access and understand health information.

1.2 Importance and effectiveness of patient information

In recent years a wide range of health information specifically aimed at patients has been developed. Some of this information focuses on procedures, treatments or services at local hospitals or GP clinics. Other information provides more detail on specific health conditions. Much of this is provided by charitable organisations,

for example, Diabetes UK (see <http://www.diabetes.org.uk/>) and the British Heart Foundation (see <http://www.bhf.org.uk/>). Furthermore there are also web-based applications that aim to help members of the public find out information about different health conditions or concerns, such as NHS Direct (<http://www.nhsdirect.nhs.uk/>). With a multitude of information sources and delivery methods available, research studies are now being carried out to assess the value of different types of patient information.

Coulter et al (2006) conducted a major review of the effectiveness of patient information. In their report they identify four key areas:

- Knowledge and recall of information
- Patient experience
- Service utilisation and costs
- Health behaviour and health status

We use these headings and briefly discuss each area in turn.

Firstly, research shows that the provision of patient information improves **knowledge and recall**. Whilst this is the case for different types of media including audiotapes/ videotapes, interactive media and patient decision aids (Santo et al, 2005; Estabrooks et al, 2001; Murray et al, 2005), it is especially true for written information (McPherson et al, 2001). Johnson et al (2003) found that combining written material with verbal information was significantly more effective in improving patients' knowledge than providing verbal information alone. Recall may differ, however, depending on the specific part of the consultation or piece of information that is being discussed. For example, Gabrijel et al (2008) examined recall of information in patients diagnosed with lung cancer and found that whilst recall on diagnosis and proposed treatment was good, recall of information around the intention of the treatment was poor.

Secondly, Mullalley (2003) argues that providing high quality information is one way of improving **patient experience**. Some studies indicate that providing patient information increases patient satisfaction (Jones et al, 2006; von Vogelsung et al 2004; Fagermoen & Hamilton, 2006; Hering et al, 2005). However this not supported by McDonald et al. (2004) who found that education (including patient information) had no effect on satisfaction in a systematic review of nine studies.

There is very little evidence on how patient information impacts on psychological outcomes. However some studies indicate that providing information prior to treatment can reduce anxiety (Howells, 1999; Humphris, 2001; McDonald et al, 2004; Hawinghorst-Knapstein et al, 2006; Sheard & Garrud, 2006; Gatson & Mitchell, 2005). The concepts of choice and decision-making in relation to information provision are debated. Jepson et al (2007) suggest that whilst information may affect satisfaction and anxiety it may play little role in how patients make choices. They suggest that the provision of information alone does

not mean that informed decisions are made. However Mayberry & Mayberry (2008), in a recent empirical study concerning patient decision making around sedation and anaesthesia during gastroscopy, suggest that the development and use of a decision tree is a useful and effective way of providing information and recording patient choice. It would seem that even if information does not contribute to the final decision made, it is best practice to support the ability to make an informed choice by providing information.

Thirdly, service utilisation and costs are important areas for the NHS. Coulter et al (2006) found little evidence for organisational outcomes in relation to patient information. However there is some evidence that information provision affects decision making. O'Connor & Stacey (2005) found when patients are provided with information and make preferences in relation to elective surgery, the uptake of surgery is reduced. O'Connor et al (2003) also found that web-based decision aids were cost-neutral compared to normal care. Johnson et al (2003) found that providing both written and verbal information on discharge from hospital reduced the rates of return visits to A&E. At the preventive end of medicine, Coulter et al. (2006) cite two studies of screening (Briss et al, 2004; Edwards et al, 2003) which indicate that decision aids that provide patients with individualised risk information increase the uptake of screening.

In terms of methods used to provide information, patients prefer health information that is delivered using audio, visual or interactive media (Coulter & Ellins, 2006). Printed information leaflets can be expensive but these costs could be reduced or negated if tailored information could be generated from patients' electronic medical records (Jones et al, 1999). These studies indicate that investment in patient information could be cost-effective.

Fourthly, there is less evidence of how general information leaflets and decision aids impact on **health behaviour and health status**. However Coulter & Ellin (2006) suggest there is some evidence for positive and neutral impacts. For example, Murray et al (2005), reviewed studies which looked at computer based health information systems for people with chronic health conditions and found benefits for both self care behaviours and clinical outcomes. Furthermore, Wantland et al (2004) indicate that such changes are also evident in groups which do not suffer from chronic illness. Individual research studies also support this view. For example, Pegg et al (2005) found patients undergoing rehabilitation for brain injury who were provided with personalised information were more satisfied with treatment, made greater effort in their physical therapy and made greater improvements in their functional independence. Similarly Tang & Newcomb (1998) found that specific personalised information increased patients' motivation to adhere to treatment plans.

One further area that is worth noting is the affect of providing information on the **doctor/ patient relationship**. Traditionally doctors have been opposed to disclosing all the details of an illness to patients for fear that patients would not

be able to cope with this (Coulter et al, 1998). However there has been a shift from patients being passive recipients of care to active partners and consumers (Byrne, 2003; Anderson, 2004).

Some professionals still feel threatened by patients finding information independently. They worry about the accuracy of the information, the abilities of the patient to understand the information, the potential for inappropriate self-diagnosis and the possible demand for unavailable new treatments (Hart et al, 2004). In addition some professionals feel there is not enough time in the consultation to respond to patients questions resulting from internet information or to search the internet to see what information their patients might be viewing (Anderson, 2004; Hollander & Lanier, 2001). In some cases patients bringing information to the consultation can lead to health professionals responding defensively and reasserting their 'expertise' (McMullan, 2006).

Despite this many studies have found that health professionals view increasing patient access to information positively (for example, Chen & Sui, 2001). Additionally, Stevenson et al (2007) found that whilst patients were increasingly active in seeking information, they had no desire to unsettle or disrupt the balance of power between the health professionals and the patients in the consultation. They argue that internet information can support the doctor/ patient relationship and that doctors should not feel threatened by internet use by patients. Indeed this is supported by McMullan (2006) who suggests that when health professionals accept that patients may bring information to a consultation this can lead to health professionals and patients working collaboratively, in a patient-centred approach and to health professionals guiding patients to reliable sources for information, or an 'information prescription' (Gerber & Eiser, 2001).

1.3 Accessing patient information

Whilst there is a great deal of patient information available and it appears that providing information is effective in many respects, it is not always easily accessible or of high quality. A number of barriers exist.

Firstly, **access to information is not equitable**. Eysenbach (2000: 1716) argues that we exist in an information age but one where, 'access to appropriate information is particularly difficult for those who need it most'. Ironically, this has been compounded by the phenomenal growth of the internet. Whilst much health information is now also sourced from the internet (Calabretta, 2002; Ayantunde et al, 2007; McMullan, 2006) and the internet is widely available, convenient and anonymous (Williams et al, 2003), not everyone can access it. Research by Dickerson et al (2004) indicates that internet use is still limited amongst disadvantaged groups. Worryingly, those who are socially or economically disadvantaged often have high social and health needs (Wilkinson & Marmot, 2003) and therefore their access to health information could be viewed as a

public health priority.

Secondly, most people access health information via health professionals. Therefore the **practices and attitudes of, and relationships between, health professionals can affect the amount and quality of information accessed**. Common criticisms are that health professionals do not provide enough information to patients (Chandler, 1996; Cegala et al, 2008) and that information provision varies between professionals (King et al, 2004; Mortimer et al, 2002). Whilst patients and carers are generally receptive of information and some groups have high information needs (Parker et al, 2007), many differences exist around what information people want and when they want to receive it (Baker, 1995; Parker et al, 2007; Payne, 2002, Vaidyanathan et al, 2001; Andreasson et al, 2005; Pollock et al, 2004). It is therefore important that individual needs and preferences are taken into account when information is provided to patients and carers. Some patients report being given information that is too generic (Tooth & Hoffmann, 2004; McKenna et al, 2003) or that is provided at an inappropriate time (Van Binsbergen & Drenthen, 2003).

In terms of relationships, Siminoff et al (2006) found that doctors differentiated between patients based on demographic factors, with doctors in one study spending more time building relationships with white as opposed to non-white patients. Moret et al (2008) examined the roles of doctors and nurses regarding information delivery and found that these were confused. The lack of collaboration between these professions adversely affected patient care and information provision. In addition poor clinician communication skills (Glenton, 2002; McIntosh & Shaw, 2003), clinicians' ambivalence towards a specific health condition or the provision of patient information in general (Pollock et al, 2004; Glenton, 2002) and the lack of time available in consultations (Anderson, 2004) all act as barriers to information provision. Patients and health professionals can also have different perspectives on whether information was provided appropriately. In some cases clinicians may feel that they have provided information in an understandable and accessible manner but then patients report otherwise (Hegney et al, 2005). Some clinicians feel ambivalent about providing information for some patient groups or feel that particular types of information should be excluded (Pollock et al, 2004).

Thirdly, the **quality of information is extremely variable**. This is noted by many individual studies (Harris, 1997; Booth-Gibbon et al, 2001; Kinrade, 2002). In 1999 Coulter et al assessed patient information materials related to ten different health problems/ treatments. They found that the quality of most patient information materials was poor. The researchers noted that many materials contained out of date or inaccurate information, that information that was relevant was often omitted, that treatment options were often not described in full and that information on treatment effectiveness was often unreliable or missing. Side effects, risks and uncertain areas were not well explained and technical terminology was used that was not easy to understand.

On the internet the sheer amount of information can be overwhelming (Eysenbach, 2003). A systematic review of internet health information targeted at patients or the public concluded that the quality of internet health information is variable and some sites contain inaccurate information (Eysenbach et al, 2002). Some sources contradict and contrast with one another (McIntosh & Shaw, 2003). This is confusing. Patients can often overrate the quality of information provided by internet sites and therefore there is a need for a critical examination of the quality of internet health information (Suarez-Almazor et al, 2001). Additionally, information is never neutral but always value laden and contextual (Payne, 2002) so there is a need for people to be able to recognise and understand the perspective of the information provider.

Fourthly, in some cases it is not the quality of the information that is queried but rather its **complexity and readability is problematic**. Information may be accurate but the inclusion of jargon or complex medical terminology can make information incomprehensible (Glenton, 2002). Many studies have found that the reading age of patient information materials is too high (Foley, 2001; Beaver & Luker, 1997; Smith & Smith, 1994; Boulous, 2005). For some groups with specific needs, such as people with learning difficulties, sometimes appropriate information simply does not exist (Strydom et al, 2001).

1.4 Improving the quality of, and access to, patient information

The quality of patient information and access to this can be improved in a number of ways and there is now much published material on developing patient information (North et al, 1996; Turnball, 2003; Tutty & O'Connor, 1999; Swain, 2003; McClune et al, 2002; Raisbeck, 2004; Grilli & Scalzo, 2001; Hutchison & McCreddie, 2007).

Firstly, a number of studies cite the **benefits of involving patients in the development of patient information materials** (for example, McIntosh & Shaw, 2003; Paul et al, 2004). This approach allows information to be developed from the patient perspective and facilitates the inclusion of information that may be of real benefit to patients but was not considered to be important by health professionals.

Secondly, patient **information should be tailored to suit individual patient needs** and learning styles (Kaur, 2004). Patient information should include clear messages (Clark, 1997) and be written in plain English (Butow et al, 1998). The needs of the target patient group should be considered. For example, a South African study that reported on the development of patient information around treatment for HIV sufferers found that pictograms were particularly well received (Mwingira & Dowse, 2006). Information needs to be carefully structured (Carrigan et al, 2004) and format, design and placement are all important (Frost et al, 1999). Additionally, information should be culturally appropriate (Wilson, 2000).

Thirdly, **information can be provided through different methods** and telephone help-lines (Collett et al, 2002), open evenings (Wellington, 2003) and audio, visual and interactive media (Coulter & Ellins, 2006) have all been well received by patients.

Fourthly, **clinicians' information providing skills need to be improved** (McIntosh & Shaw, 2003) and Jones et al (2001) suggest that learning outcomes identified for clinicians in relation to patient information could be incorporated into teaching curricula. A patient-centred approach should be used (Bergvik et al, 2008) and Greenwood (2002) argues that nurses have a role in supporting patients to access information. Whilst time is a constraint in consultations, clinicians must find time to make sure that patients understand the information provided.

1.5 Patient information and the NHS

In the UK, the government is committed to increasing patient involvement in healthcare and over the past 8 years a number of different initiatives and policies have been launched by the Department of Health. These range from the Expert Patients Programme (EPP) in 2001 to 'Our health, Our care, Our say' (DH, 2006) and the agenda around patient choice.

All of these policy directives place information at the core of health services and health policy.

In 2003 the Department of Health conducted a national consultation on choice, equity and responsiveness. Nearly 90% of respondents said that in order to make informed choices about their health they need the right information, at the right time with the support to use it. This was followed by the publication of a patient information strategy for the NHS, *Better information, better choices, better health: Putting information at the centre of health* (DH, 2004b). This strategy was premised upon several key issues (a) the need for access to high quality information (b) equitable access for all (c) that access to information can improve the partnerships between health professionals and patients which in turn can lead to better health outcomes.

The strategy aimed to embed information as a central part of the healthcare system, to develop a single approach to information, to make information more effective and to help people participate confidently in their healthcare. A number of national systems were proposed including a translation/ interpretation service, health trainers to support people to make healthy choices, sources of clear and authoritative information, access to health records and campaigns to help people recognise quality information. In addition a number of concepts in relation to personalised information were outlined:

- Power questions – the development of an essential set of questions that patients can ask health professionals
- Information prescriptions – time set aside within the consultation should be used to discuss concerns, fears and information needs. This can be recorded and reviewed and patients can be provided with an information prescription which would signpost them to areas of information and support
- Copying letters to patients so that they know what is being done regarding their care and treatment
- Training in communication and listening skills and empathy for health professionals.

Finally, the strategy outlined that organisations such as NHS trusts have responsibilities for providing information to patients and that the provision of information, in an equitable manner, will be performance managed.

1.6 The Knowledge and Information Centre (KIC) at St Thomas' Hospital

The Knowledge and Information Centre (KIC) opened in April 2004 at St Thomas' Hospital as a comprehensive resource centre, offering Trust-wide access to a wide range of health related books and leaflets, internet and email facilities, details of local and national support groups and information drop in clinics. As the Trust Joint Director of Clinical Leadership said at the time, "The KIC is an important step towards empowering patients and helping them to understand more about their own medical condition. It can also help them to access local and national support services which can help and advise them once they have left hospital."

The KIC is based on the site of the old patients' library at St Thomas' which was created in the late 1940s with funds from the Special Trustees. With the formation of the Guy's and St Thomas' Charitable Foundation and the introduction of new rules and guidelines regarding recurrent funding, the direction of operation needed to change in response to 'the information age'. A successful bid to the Charitable Foundation (now GSTT Charity) represented a three year plan for the development of a new and innovative information resource.

The KIC aims to provide health information, information on support groups and local services to patients, staff and visitors and is at the forefront of good practice in this field. However, it is also somewhere for them to relax, read a newspaper or keep in touch with friends and family via email.

It should be noted that since January 2007, the remit of the KIC has broadened to incorporate patient information, PALS (Patient Advice and Liaison Service) and Voluntary Services. This has resulted in a more holistic service being offered

from the KIC in support of patients', relatives' and carers' health care concerns and information needs.

It is in this context that we approached the evaluation of the KIC at Guy's and St Thomas' NHS Foundation Trust in Lambeth and Southwark, two inner city London boroughs with high levels of deprivation and health needs.

Section 2: Evaluation of the KIC

2.1 Evaluating patient information provision

There have been a number of evaluative studies which consider information provision for specific groups of patients, in particular formats, through different media. However, relatively few studies have been carried out to evaluate the impact of patient information services as a whole, particularly those that deliver services through a wide range of media like the KIC.

Although findings from earlier studies have been informative in terms of identifying training needs for staff and developing the resource base of information provision, these studies have tended to focus on specific issues. Examples include the process of setting up and establishment of more specialist resources centres such as those for cancer patients (Edleman & Warren, 1994), the evaluation of individual leaflets (Entwistle & Watt 1998) and services which provide both *advice* and information for patients (Montazeri, 1999).

More recently researchers have tended to focus on the impacts and benefits of information provision for patients via new technologies. A US based study (Goldschmidt & Goodrich, 2004) into the use of touch screen kiosks suggested benefits in terms of vaccination uptake by patients, whilst a UK study (Nicholas et al, 2001) considering the same technology highlighted positive outcomes for patients but raised concerns regarding ease of use and information literacy. Another recent study (Homewood, 2004) examining consumers use of web-based interactive services such as email enquiry services and discussion boards raised issues around the suitability of questions asked and the ability of users to easily find information.

Published reviews of NHS Direct services have addressed issues of activity, costs, callers' views, impact and safety. Impact in this context relates to the overall volume and distribution of demand for health care attributable to NHS Direct (Munro, 2003)

Again all of the above studies tended to focus on the impact of individual methods of information provision rather than an information service as a whole. A recent study (Adab, 2004) of an arthritis resource centre looked at a range of information resources but focused on information needs and provision rather than the impact of the service on its users. A key recommendation of the study was the need to investigate further the effectiveness of the provision of good quality information to patients.

2.2 Background to, and purpose of, the evaluation

In 2006 the KIC was successful in obtaining funding to evaluate its services from the Cicely Northcote Trust and the Guy's and St Thomas' Charitable Foundation, later GSTT charity. The Cicely Northcote Trust was keen to fund this evaluation in order to explore the possibility that the KIC model or service could be developed and extended into primary care. London South Bank University was commissioned to undertake the evaluation. £19,500 and £16,000 was received from the Guy's and St Thomas' Charitable Foundation and the Cicely Northcote Trust respectively. This funding supported one research fellow on a part-time (2.5 days per week) basis for 2 years and covered basic research costs.

The primary aim of the evaluation was to explore the impact, both intended and unintended, that the KIC had on its users. The evaluation also explored some of the key experiences that the users had of the KIC services.

The evaluation hoped to contribute to research into the area of patient information as a whole and involve users in the design of the study. This aspect has been lacking from previous work so the project aimed to be innovative in its methodology in that respect.

The KIC provides many services but this evaluation concentrated on the group of users for whom a detailed assessment of their health information needs was made by KIC staff (i.e. who made use the 'complex enquiry service'). Complex enquiries can be defined as requests from patients, their carers, families or visitors for detailed and in-depth information about an aspect of a condition. For example, a research article on the mechanisms of action of HDL and LDL lipids or information on a rare condition. Often these information requests cannot be met using the main patient information collection and require further research on medical research databases or specialist websites.

The evaluation focused on this user group for two main reasons. Firstly, these users would have experience of dealing with staff and the information finding service. Secondly, from a good practice perspective the steering group wanted to make sure that only KIC clients who had indicated that they would be happy to provide feedback on the KIC service were contacted. This was indicated on the complex enquiry form and meant that the research team could avoid contacting people who did not wish to take part or who felt unable to due to their own circumstances.

During the period of the evaluation the KIC service changed significantly and this impacted on the ability of the service to engage proactively with it's users. By the end of the project the KIC service had merged with two other services and looked very different to the service that existed at the beginning of the evaluation.

2.3 Evaluation methods

The evaluation of the KIC utilised both quantitative and qualitative approaches and involved two distinct phases of survey data collection and interview data collection. Two questionnaires were developed by the research team in partnership with the KIC user group. Input was also provided by the Steering Group. Questionnaires were piloted with a number of service users and adjustments to terminology, content and the structure of the questionnaire were made. In addition a list of interview questions was drawn up and feedback on these was provided by the Steering Group.

Questionnaires were chosen as they are an objective and effective method of reaching a large number of people and obtaining information on views, attitudes and knowledge (Oppenheim, 1992; Sapsford, 1999). Qualitative research was felt necessary to provide rich data and further explanation of information gleaned from the questionnaires. Qualitative data adds depth and meaning and gives us the ability to hear participants' voices in their own words (Denzin and Lincoln, 1994).

Phase 1: quantitative, questionnaire data

The first phase of the study, which took place between October 2006 and December 2007, involved the use of questionnaires. Clients were asked to complete two different questionnaires at two different points in time. The first questionnaire (referred to as the baseline/ experience questionnaire) dealt exclusively with the client's experiences of the KIC service. All clients who had used the complex enquiry service were invited by the KIC staff to complete this questionnaire and to deposit it in a specially designed, anonymous 'survey drop box' located in the KIC when they first used the service.

Those clients that indicated on the baseline/ experience questionnaire that they would be willing to complete a further questionnaire then completed a second questionnaire (referred to as the follow-up/ impact questionnaire) either face-to-face or over the telephone one month after they had first used the complex enquiry service. This follow-up questionnaire dealt exclusively with the impact that the information clients received from the complex enquiry service had on their lives. Waiting for a period of one month before administering the follow-up/ impact questionnaire gave time for clients to absorb and make use of the information that they had received from the KIC staff.

A copy of both questionnaires can be found in Appendix One and Appendix Two.

130 baseline/ experience questionnaires were distributed to KIC users by KIC staff over a period of 12 months (June 2006 – June 2007). **In total, 61 (47%) clients returned a baseline questionnaire.** Of the 61 clients who completed a baseline questionnaire, 48 (78%) clients agreed to complete a one month follow-up/ impact questionnaire. **Of these 48 clients, 36 (75%) actually completed a**

follow-up/ impact questionnaire with a researcher; the remaining 12 clients either withdrew consent (3 clients) or could not be contacted (9 clients).

Data for 2006/07 from the KIC service indicates that approximately 67 people per month asked KIC staff for help in finding health information and that approximately 20 of these were classed as complex enquiries. Therefore during the questionnaire data collection period we would have expected 240 questionnaires to be distributed. The actual distribution was significantly less than this and this was in most part due to the fact that the KIC service went through a period of significant change and merger with 2 other services. This period of reorganisation was a source of considerable stress and increased workload for the KIC team and meant that the evaluation could not be prioritised as had been originally intended.

This being said the difficulties of achieving high questionnaire response rates are well documented (Edwards, 2002) and we feel that the 47% response rate to the baseline questionnaire is acceptable; particularly when many of the potential respondents may have been experiencing difficult personal circumstances due to ill-health.

Questionnaire data were inputted into SPSS v 13.0 – a software programme used for statistical analysis – and analysed using descriptive statistics and frequencies.

Phase 2: qualitative, interview data

The second phase of the study, which took place between September 2007 and January 2008, involved the use of qualitative interviews. The purpose of the interviews was to explore some of the issues raised in the survey phase of the study in more depth, as well as allowing participants to recount their experiences of the KIC in their own words. A copy of the interview topic guide can be found in Appendix Three.

Interview participants self-selected in that they indicated on the follow-up/ impact questionnaire that they would be happy to participate in an interview. All were contacted by telephone with an explanation of the study. Potential participants were also given an opportunity to ask any questions and to withdraw if they wished to do so. Out of the 36 participants who completed a follow-up questionnaire, 22 consented to taking part in further interview work. **Out of these 22, 18 participants were able to take part in the actual interview.** The remaining four clients could either not be contacted or withdrew consent.

Clients were offered the choice of being interviewed on a face-to-face basis or over the telephone. Face-to-face interviews were carried out in a confidential and safe environment either at the KIC or in another room at St Thomas' Hospital. All interviews were conducted in English and lasted no longer than one hour. Where possible, the interviews were recorded and the tapes fully transcribed for

analysis. The researcher also made notes throughout each interview for clarity and ease of reference.

The analysis of the transcripts was thematic in nature. This entailed identifying and refining the themes emerging from the data, identifying and exploring the relationships between themes, and where appropriate linking the literature to themes identified. This enabled the study to convert the key messages into implications and recommendations for the improvement of KIC.

Finally, it is worth noting that, in order to capture accurately the meanings, experiences and views of the participants, all the quotes are presented in their verbatim form in this report. Therefore, the grammar used in these quotes reflects how the participants actually structured their speech in the interviews. Furthermore, the interviewer's questions and comments are also sometimes included in the quotes so that the context which frames the participants' responses is captured.

2.4 Limitations of the study

Despite every attempt to make the research design robust, this study, as with all research, has some limitations which need to be considered when interpreting and generalising the findings. In the first instance, the sample size for both the survey phase of the study (N= 61 at baseline and N=36 at follow-up) and the interview phase of the study (N=18) was relatively small. This was influenced by, firstly, the relatively small amount of research funding and, secondly, the organisational change which affected the ability of the KIC service to engage proactively with users during the data collection period. This study does not purport to provide an exhaustive view of all users of the KIC complex enquiry service.

Another set of limitations concern the actual composition of the sample itself. It must be noted in the first instance that this study focused only on clients that used the complex enquiry service at the KIC; thus the views expressed in this study may not consistently resonate with the views of the users of the broader portfolio of KIC services. Finally, as indicated by the statistics relating to participant characteristics, English was the first language for the majority of the clients. This study, particularly the survey phase, implied a degree of understanding of English from potential participants. As such, the views of those for whom English may not be a first language, or for whom literacy may be an issue, may be under-represented in this study.

2.5 Ethics and governance

All research conducted in the NHS requires ethical approval prior to its

commencement. For this evaluation we applied for ethical approval from the Guy's Research Ethics Committee. We were informed that the nature of the project meant that it did not require ethical review under the terms of the Governance Arrangements for Research Ethics Committees in the UK. The project received ethical approval from Research Ethics Committee in the Faculty of Health and Social Care at London South Bank University. Additionally to comply with NHS Research Governance requirements we registered the project with the Guy's R&D Department.

2.6 Project management

The evaluation was conducted by a research team at London South Bank University. This included Shoshanna Garfield and Dr Mehul Kotecha (0.5WTE) who collected data and analysed the findings and Amy Scammell and Prof Gill Rowlands who supervised the project and provided senior research input as required. Sarah Allen at the KIC provided unfunded support in terms of co-ordinating the collection of data from KIC users and facilitating the involvement of the KIC User Group in the questionnaire development.

The evaluation was monitored by a project Steering Group. The Steering Group comprised of the research team at London South Bank University, two members of the KIC user group (Eddie Farrell and David Edwards), a representative from the Cicely Northcote Trust (initially Nigel Bateman and latterly Janet Wells) and two key staff members at the KIC (Liz Fairclough and Sarah Allen). The Steering Group met 8 times over the course of the study and were responsible for the ensuring project progress was made, discussing any design or recruitment issues, commenting on initial and interim analyses of both quantitative and qualitative data and overseeing the dissemination plans and final reporting.

Section 3: Our participants

This section illustrates the demographics of the baseline/ experience questionnaire participants and the interview participants. This information can also be found in tabulated form in Appendix Four.

3.1 Demographics of baseline/ experience questionnaire participants

The following pie charts provide a breakdown of the demographic characteristics of those who completed a baseline/ experience questionnaire.

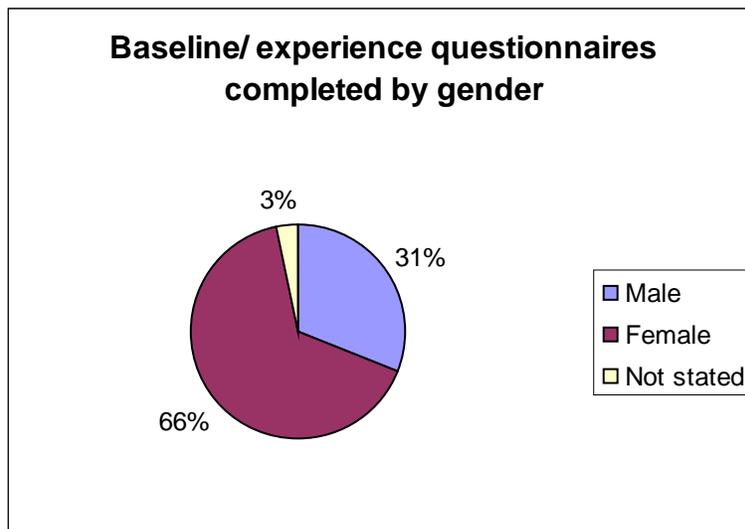


Figure 1: Baseline/ experience questionnaires completed by gender

The majority of the respondents who completed a questionnaire at the baseline measurement time were **female (66%)**. This could suggest that women are more comfortable asking for help or more inclined to proactively access health information. It could also mean that women are more likely to participate in research or evaluation studies.

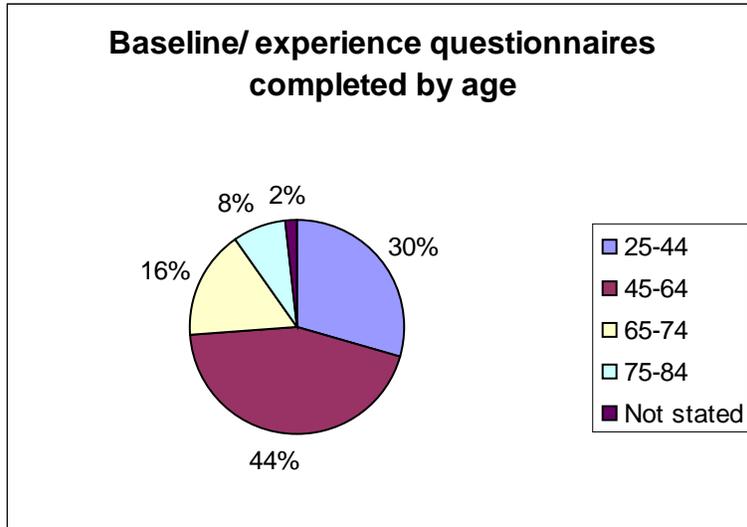


Figure 2: Baseline/ experience questionnaires completed by age

In terms of age, no respondents were aged between 16 and 24 years. This could be because these individuals are less likely to have health concerns or are more able to access information themselves through the internet. **30% of respondents were aged 25-44 years and 44% were aged 45-64 years.** It was reassuring to note that there was some representation from other, older age groups in the sample.

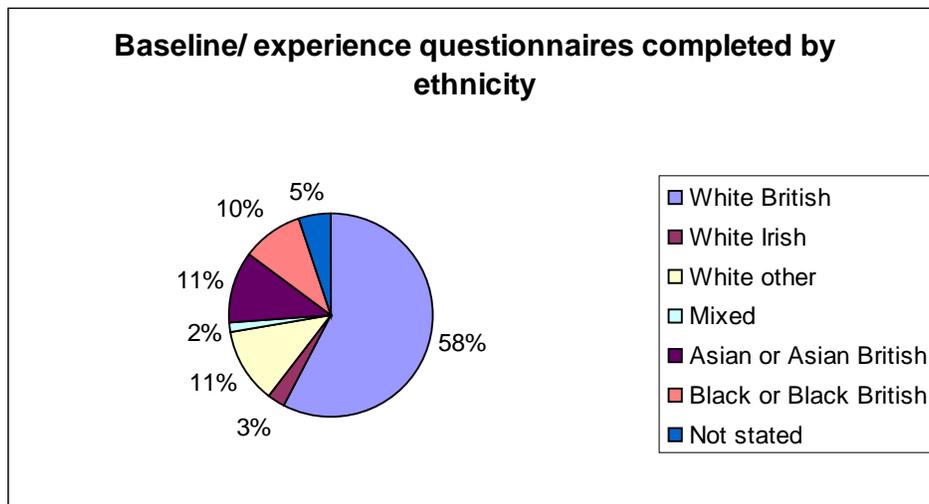


Figure 3: Baseline/ experience questionnaires completed by ethnicity

With regards to ethnicity, the majority of the respondents considered themselves to be 'white' (72%), with the **category 'White British' (58%) being the biggest single ethnic category** in the sample. There is some representation of non-white ethnic groups; accounting for 23% of the sample.

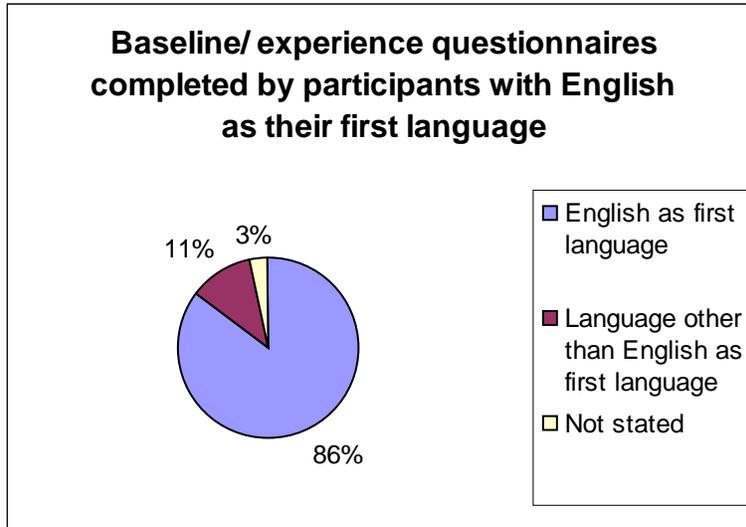


Figure 4: Baseline/ experience questionnaires completed by participants with English as their first language

The majority of the sample had **English as a first language (86%)**.

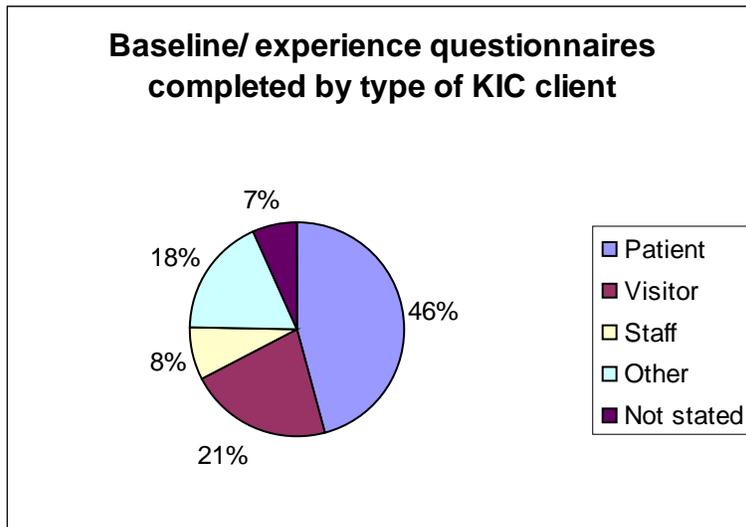


Figure 5: Baseline/ experience questionnaires completed by type of KIC client

Finally the majority were **either patients (out or inpatients) at St Thomas' hospital (46%) or visitors (21%)**.

3.2 Demographics of follow up/ impact questionnaires

The following pie charts provide a breakdown of the demographic characteristics of those who completed a follow-up/ impact questionnaire.

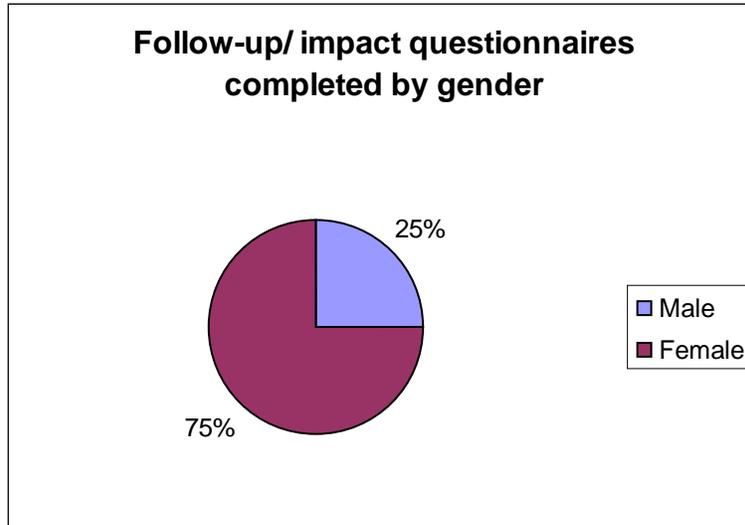


Figure 6: Follow-up/ impact questionnaires completed by gender

The majority of the respondents who completed a questionnaire at the follow-up time were **female (75%)**.

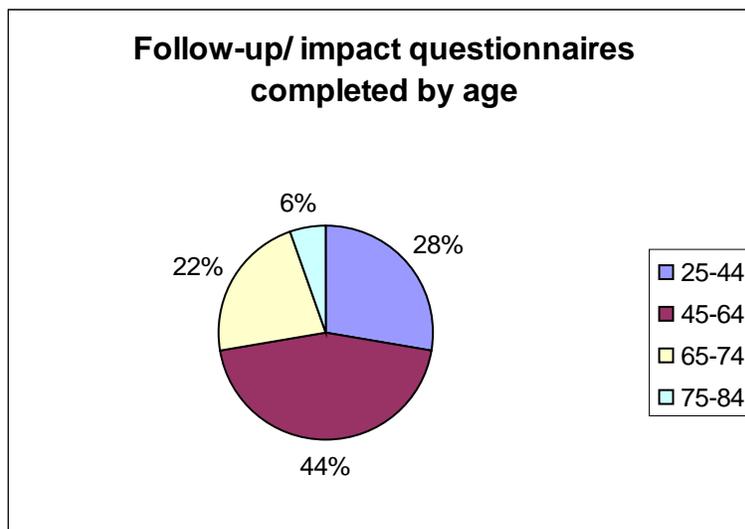


Figure 7: Follow-up/ impact questionnaires completed by age

In terms of age, again as with the baseline/ experience questionnaire there were no respondents in the 16-24 year old category. A similar split is seen between the other categories with **28% of people being aged between 25 and 44 years and 44% being aged between 45 and 64 years**. Again it was reassuring to note that there was some representation from the other, older age groups in the sample.

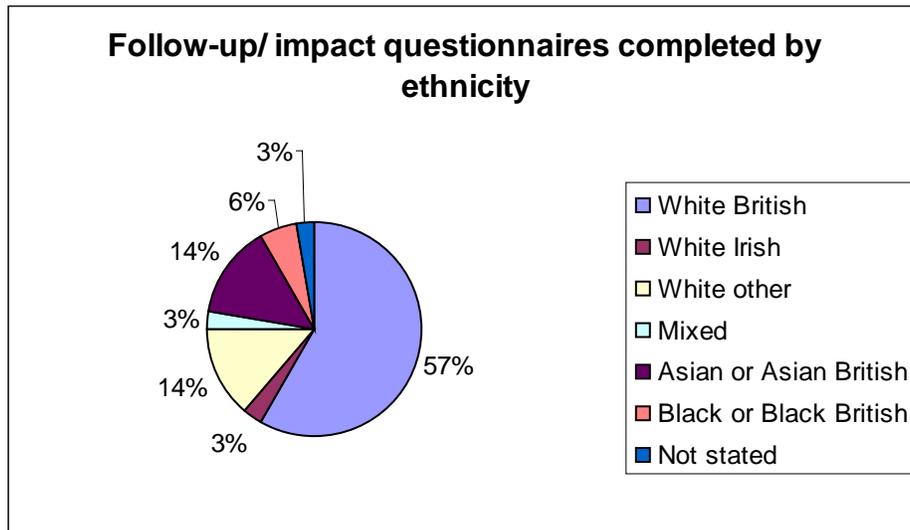


Figure 8: follow-up/ impact questionnaires completed by ethnicity

With regards to ethnicity, the majority of the respondents considered themselves to be **'white' (74%)**, with the **category 'White British' (57%) being the biggest single ethnic category** in the sample. There was some representation of non-white ethnic groups, accounting for 23% of the sample.

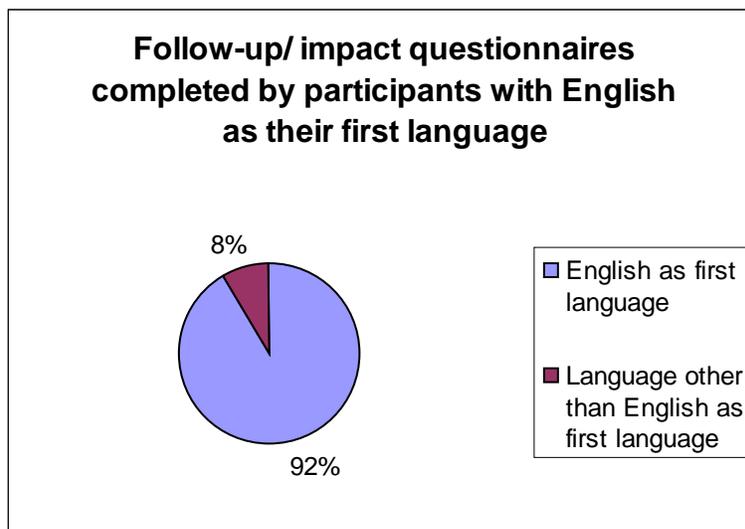


Figure 9: Follow-up/ impact questionnaires completed by clients who had English as their first language

The majority of sample had **English as a first language (92%)**.

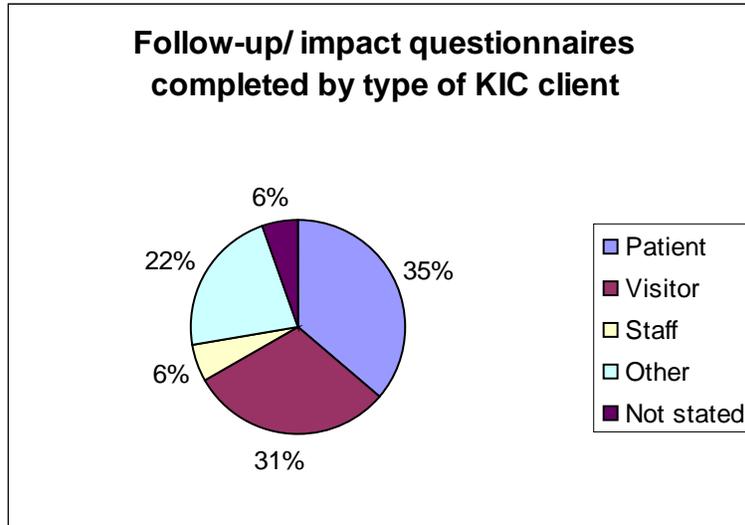


Figure 10: Follow-up/ impact questionnaires completed by type of KIC client

Finally the majority were **either patients (out or inpatients) at St Thomas hospital (35%) or visitors (31%)**.

Unfortunately, due to the relatively small number of respondents who returned a follow-up questionnaire, it was not possible to determine whether or not there were any significant differences in the demographic characteristics between those that completed a baseline questionnaire and those that eventually returned a follow-up questionnaire. The only valid comparison that could be made between both measurement times concerned the variable 'gender'. There was no significant difference. (See Appendix Four for more details).

3.3 Demographics for interview participants

The pie charts that follow below show the demographic characteristics of those who participated in the interviews.

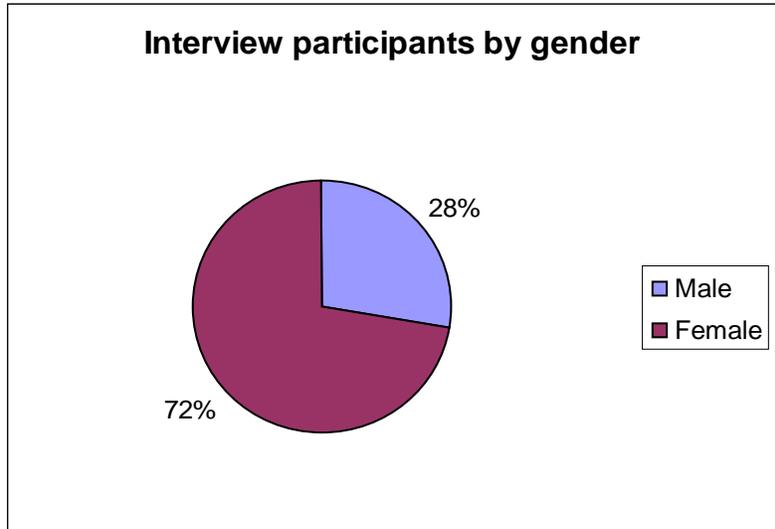


Figure 11: Interview participants by gender

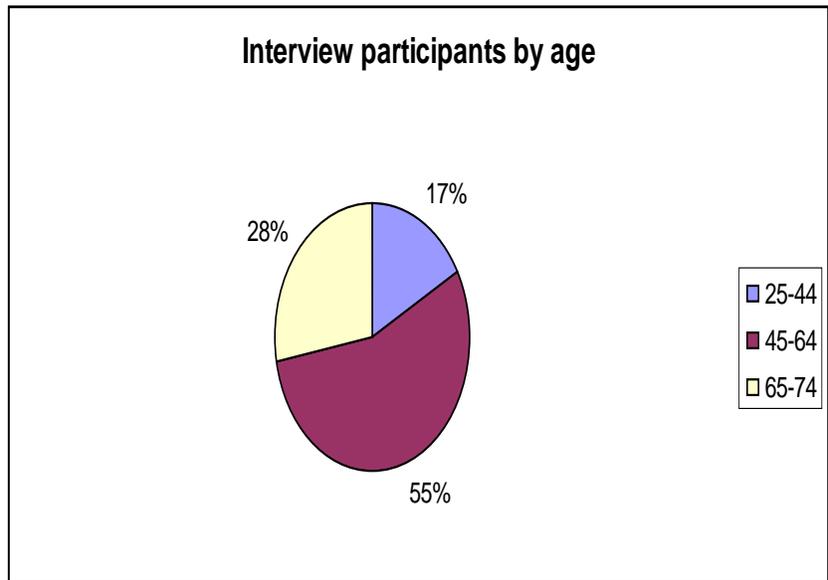


Figure 12: Interview participants by age

The majority of interview participants were **female (72%)** and **aged between 45 and 64 (55%)**. In the interviews no participants were aged over 74 years. This may reflect difficulties in participation or access for older age groups.

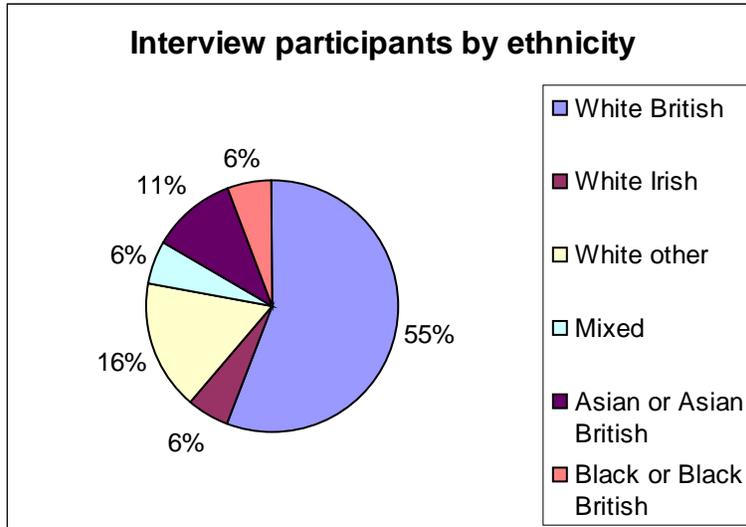


Figure 13: Interview participants by ethnicity

With regards to ethnicity, the majority of the respondents considered themselves to be 'white' (77%), with the category 'White British' (55%) being the biggest single ethnic category.

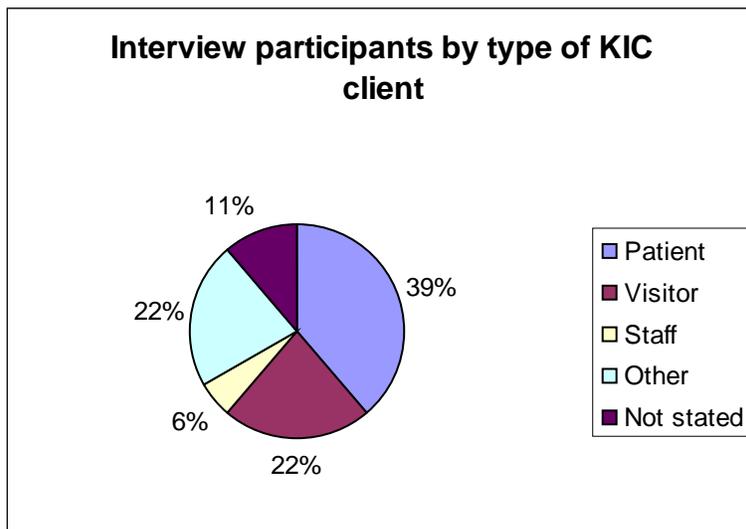


Figure 14: Interview participants by type of KIC client

All of the interviewees had English as a first language (100%) and were either patients (out or inpatients) at St Thomas hospital (39%) or visitors (22%).

Section 4: Experience findings

In this section we discuss findings related to people's experience of the KIC. These were captured in the baseline/ experience questionnaire and in interviews. We discuss how people found out about the KIC, initial impressions, the KIC environment, reasons for using the KIC, dealing with the KIC staff and the information provided by the KIC.

4.1 Finding out about the KIC

In order to use the services that the KIC offers participants first had to find the KIC. We did not ask about this in the questionnaire phase but it was discussed with interview participants. **Interview data suggests that half of the participants simply noticed the KIC service in passing as a result of using St Thomas' Hospital**, either as a patient or in the process of visiting a patient.

I saw it as I was walking through to the Dermatology Department... it's actually on the corridor on the way to the Dermatology Department... I just happened to notice that and saw something outside and I thought well that sounds good you know (KIC A)

I mean because I was walking there, I didn't know St Thomas' very well so of course when I saw it I walked in and then I walked around and every time I did a little more of that (KIC F)

I: Did you know it [the KIC] existed?

P: I didn't know. I hadn't got a clue. It used to be a medical library, one of the medical libraries and it closed down many years back.

I: How did you hear about it?

P: I walked past it [laughter] (KIC H)

There were a few participants that were referred to the KIC service by health care professionals. Often, these health care professionals that referred the clients to the KIC worked in St Thomas' themselves.

Well I had a very bad experience at Thomas'. I was in the hospital having an operation that went wrong. It went terribly wrong and I was unable to get any help from anybody and... one of the nurses mentioned to me about KIC and I have to say they are the only people in the whole hospital who appeared to have any knowledge about anything and were prepared to help me. And that's how I came to go to them (KIC B)

I: And who told you about the Knowledge and Information Centre?

P: One of the workers there

I: Workers? So a doctor?

P: Yeah one of the opticians. Because I went to see Dr XXX that day and it was her that told me (KIC C)

I was visiting St Thomas' because I was taking part in a XXX study... there were some fairly long periods of time, when they didn't actually need us, we had to wait between their investigations... so we needed somewhere to go. And because the place where we were having the investigations done was just along the corridor from the Knowledge and Information Centre, they agreed with the staff there... that we could spend some time there if we wanted to (KIC D)

Other less frequently cited ways of hearing about the KIC service included the following:

- Working/ volunteering at St Thomas';
- Work colleagues and relatives;
- Publicity leaflets about the service.

4.2 Finding the KIC

Eighty-five percent of baseline/ experience questionnaire respondents felt that the KIC was easy to find. However in interviews some respondents felt that there was a need for better signage to the KIC and more information saying that KIC was there.

When you're first in and you might need help you wouldn't know it was there because there's nothing up on the ward either to say about it (KIC B)

I think that they might advertise it a bit more. As you said to me 'how did I find it?' It just happens that I do look around a lot when I'm walking along, but I think it perhaps could be made more, perhaps advertised more in a way that when people are walking along, it would be quite easy to miss it I would think because actually I did have to ask a second time where it was because I couldn't actually remember you know? And I think that maybe it could be signposted and made a bit clearer... it may well be signposted but maybe not enough for people to notice (KIC J)

4.3 First impressions of the KIC

First impressions were resoundingly positive. Interviewees were impressed and surprised that KIC existed.

I was quite impressed actually because again, as I said, I used to be an advice worker and we never, never had the half of what you have, well, what was available at St Thomas'. So my impressions were really, you know, I was quite bowled over with it to be honest (KIC J)

You walked in and it was obvious you could get help (KIC I)

It was just that I walked in and I was greeted by this lady, smiling face... and very, very willing to help me you know... the layout was quite, yeah, it was quite impressive. They had other computers there and people were using them and stuff like that, you know, yeah, I was quite impressed when I walked in (KIC E)

I found it really welcoming like it was really quiet and somewhere you could really relax and the staff very approachable (KIC C)

Some were not entirely clear about what KIC was when they first went there:

P: It wasn't very clear to start with... because you know... the crowd was all mixed, it's not like professional doctors or nurses or anybody, it was all public, there was staff, there was...

I: You mean the people using it?

P: The people using it.

I: It was a mix of people?

P: Yeah, I'm talking about the crowd that uses it and then of course there were newspapers, there were medical books... you know it was a lot of many things (KIC F)

However the first impression for several participants was one of the KIC being a library:

It was obviously sort of a, where you could ask for more information, like a reference library where there's always somebody at a desk (KIC I)

It was my first time I'd ever visited the Information Centre so first of all I thought it was like a library (KIC G)

These comments indicate that KIC promotes a good first impression and that any

initial uncertainty seems to be countered by the atmosphere and the resemblance to a familiar service - a library.

4.4 Physical accessibility of the KIC

In order to gauge accessibility for the KIC users, in the baseline/ experience questionnaire we asked clients if they had any physical or other difficulties that would make it hard for them to use the KIC. Eighty-seven percent of respondents stated that they had no difficulties. Ten percent indicated that they had some difficulties and these included:

- Not being able to use a computer
- Users other than staff or patients occupying the computers
- Visual difficulties
- Social phobia
- Housebound
- Sciatica making it difficult to visit the KIC

None of the participants in interviews saw themselves as having accessibility problems although one was photosensitive and one used a hearing aid. Despite this **many commented that they thought the KIC facilities and KIC information would be accessible to those with physical difficulties:**

If you was in a wheelchair it was easily accessible because I think they have laptops as well and lower desks (KIC C)

It [the information] wasn't too small because I know sometimes when you print off things from the internet it can come out quite small. No, the print was absolutely fine and it was quite easy to read, they had pictures on there so yeah it was very informative (KIC G)

As we saw in section 3 the majority of people who accessed the KIC had English as their first language and everyone was able to converse in English. However one interviewee suggested that **access to the KIC services would be restricted for people whose English language skills were limited.**

4.5 The KIC space and environment

Overall respondents viewed the KIC environment positively. In the baseline/ experience questionnaire we asked clients to indicate their agreement with four statements related to the KIC environment. The chart below illustrates respondents' views:

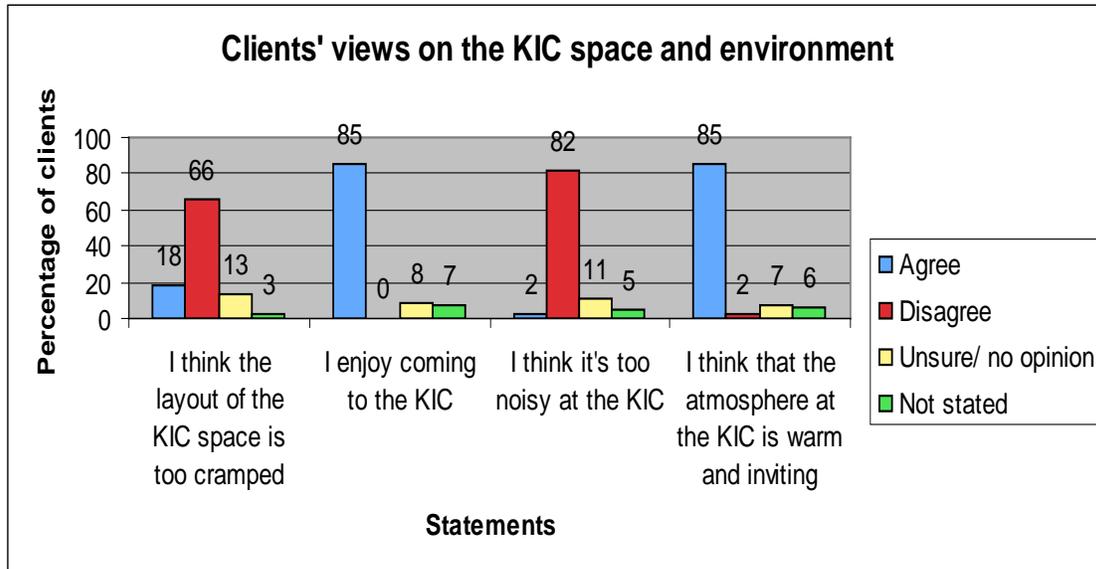


Figure 15: Clients' views on the KIC space and environment

From the above chart we can see that **the majority of respondents:**

- **felt that the KIC space is appropriately spacious (66%)**
- **enjoyed coming to the KIC (85%)**
- **felt that the KIC provided a warm and inviting atmosphere (85%)**
- **felt that the KIC was appropriately quite and peaceful (82%).**

Interview participants supported these positive views of the KIC space, layout and atmosphere.

You had the space, there was also the space if you needed to go off and do any kind of research on your own, the facilities were there also... the way, the computer tables were laid out. Even the reading area was again, comfortable, well-placed. (KIC J)

It was nicely laid out in terms of space. There were chairs and tables if [they] have a meeting and it was clean and professional environment that you'd feel at ease in (KIC H)

I mean there were a few people using it. I mean it wasn't crowded or anything (KIC I)

Well, here was plenty of space and what I liked about it was that erm, they had a, a chair in front of the counter, and you could sit down. It was a bit more personal (KIC E)

P: It was like really quiet and somewhere where you could really relax and staff were very approachable

I: ...What made you feel relaxed in that area, do you know?

P: I think it was the soft chairs and the furnishing.
 I: What about the furnishing?
 P: The furnishing was like really comfortable; it wasn't hard chairs to sit on.
 I: Ah, soft chairs. Ok.
 P: It was like as if you was in a lounge in your own house (KIC C)

Basically the only two places in the whole hospital where there wasn't mayhem was the KIC and the children's section, the rest was an absolute nightmare, so I used to find it quite nice to go down there and it was good... I did find KIC a haven (KIC B)

Two interviewees made comments regarding the environment. One felt that the **television should be in a separate room to give people the option to watch it properly** if they wished. The other suggested a **chair by the kiosk** outside of the KIC door.

4.6 Clients' reasons for using the KIC

The findings for this section stem from both the baseline/ experience questionnaire data, and the interview data. Participants were asked in the baseline/ experience questionnaire to indicate their reasons for using the KIC. The chart below summarises these findings. A table illustrating these data can be found in Appendix Five.

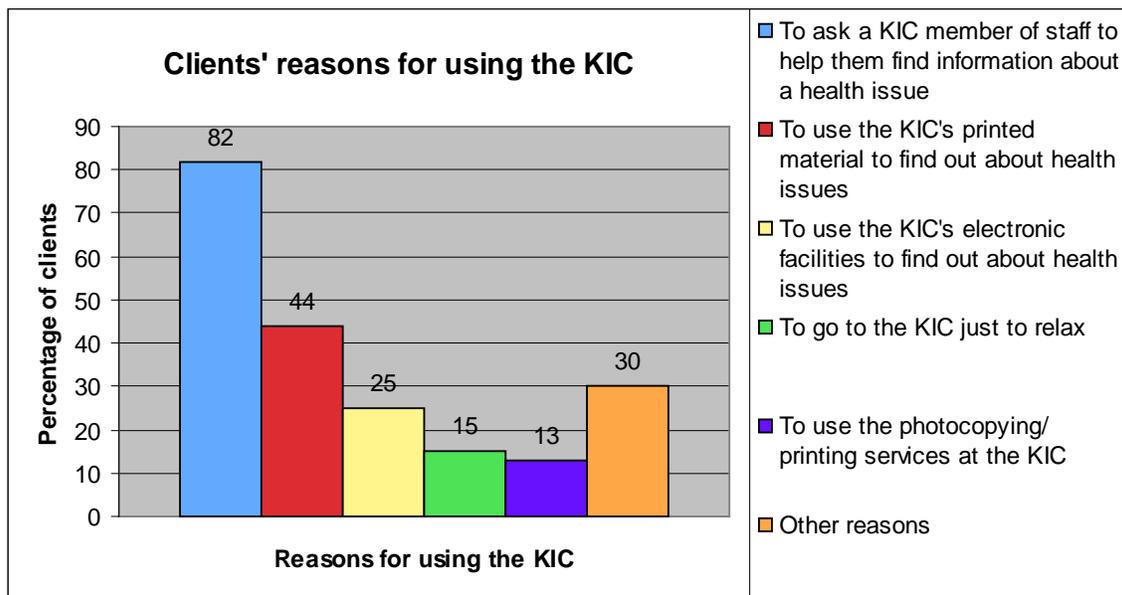


Figure 16: Clients' reasons for accessing the KIC

As the above chart illustrates, the majority of the participants (82%) used the KIC services for health-related reasons. This is indicated by the fact that

the use of KIC for health-related reasons accounted for the top three reasons why clients chose to use the KIC in the first place. Given the nature of the sample (i.e. consisting of all those individuals who had used the complex enquiry service), it should come of no surprise that the majority of the participants used the KIC service to ask a member of staff to help them find out information about a health condition.

4.7 Finding health information

The questionnaire data suggests that the majority of the participants (63%) requested the health information for themselves. To a lesser degree, 16% of participants requested the information for someone else such as a friend, relative or partner.

The interview data supports some of the above findings. The data suggests that the majority of the interviewees (83%) used the KIC for health-related reasons. 61% used the KIC to find out about a specific health condition. These ranged from skin conditions to chronic diseases (e.g. blood conditions). Three participants wanted to find out about specific treatments and therapies and various surgical procedures. One participant wanted to find out more information about medical test results.

I needed more serious information which was about the friend with Asperger's Syndrome... and so I started reading a lot about autism and they don't live in the UK so I kind of looked into for advice and stuff, and also for me to understand the child better, I thought it was better to read it because they are very close to me. (KIC F)

I sort of immediately said I'd got this test result that I didn't understand (KIC D)

I'd previously enquired about leaflets for patient transport for my neighbour also in sheltered housing... I'd been to an official appointment here and I thought 'oh I'll go in there and ask about the Alexander technique...' it suddenly struck me that they might be able to point me in a direction of a book or a net reference for anything (KIC C)

My daughter has a blood disorder and we knew very little about it and because there's a history of blood disorders in the family my GP decided, you know, suggested that I go get tested. And I got tested and they said I had some disorder. And I didn't know what, anything about it. And of course if you've got no medical background it's really hard, the local libraries don't supply you with that many medical dictionaries etc. And somebody, when I was in

St Thomas', somebody mentioned that the advice centre was there (KIC J)

One of my sister's grandchildren has cerebral palsy in India so I was looking for chairs you know special material for a child because there they don't have very advanced chairs and things (KIC F)

4.8 Asking the KIC staff for help

Clients asked members of staff for help for a variety of reasons. Some of the key reasons are listed below:

- They just **wanted someone to help them** (N¹=13);
- They **could not find the information they wanted** on their own (N=7);
- They were **unable to use the IT facilities and services** available at the KIC (N=6);
- They were **referred to the KIC** staff by health professionals so felt they should ask staff (N=5);
- It was **convenient** just to ask a member of staff for help (N=5);
- They were **unable to search the printed material** for the information they needed (N=3);
- They felt **overwhelmed by the amount of information** (N=2);
- They had **limited time** so therefore thought it more expedient to ask a member of staff (N=2).

Interview data supports the fact that many participants felt unable to access the information themselves largely because they weren't sure how to go about this or were not able to use IT facilities or services.

I wasn't too sure if it was for staff only or whether patients could use it, what I could use those things for so basically a member of staff in the Information Centre helped me look up the specific thing I wanted (KIC G)

You know, I myself can't use a computer and they were willing to help me and get information for me even though I couldn't use a computer (KIC B)

I was in the hospital and I was suffering from migraine and once before I was told that there was a website on the computer up there, and because I'm not computer literate I asked one of the staff if they could help and they were very obliging (KIC C)

¹ 'N' refers to the number of participants that agreed with specific statements.

I was lucky the first time I went in because there was a young woman there and she was very, very helpful and she went out of her way to print out literature for me and you know you just put herself out completely. In fact I think she even phoned me at home and she even wrote to me because I was going back again because she was going to try and sort out further information for me (KIC A)

She was able to help straightaway... she was kind of able to kind of go on a computer, on the, on the KIC website, but she also knew other sites, where there could be information (KIC I)

4.9 Service provided by the KIC staff

Participants were overwhelmingly positive about the service provided by staff. The following interviewees sum up many comments:

The person who helped me was... I thought it was just utterly superb. She over delivered (KIC K)

It was quite enlightening because I didn't expect all that service just for one simple question... And it's a pleasant service as well (KIC L)

In the baseline/ experience questionnaire we asked clients to indicate their agreement with 7 statements relating to dealing with KIC staff and the information provided. The responses can be seen in the chart below.

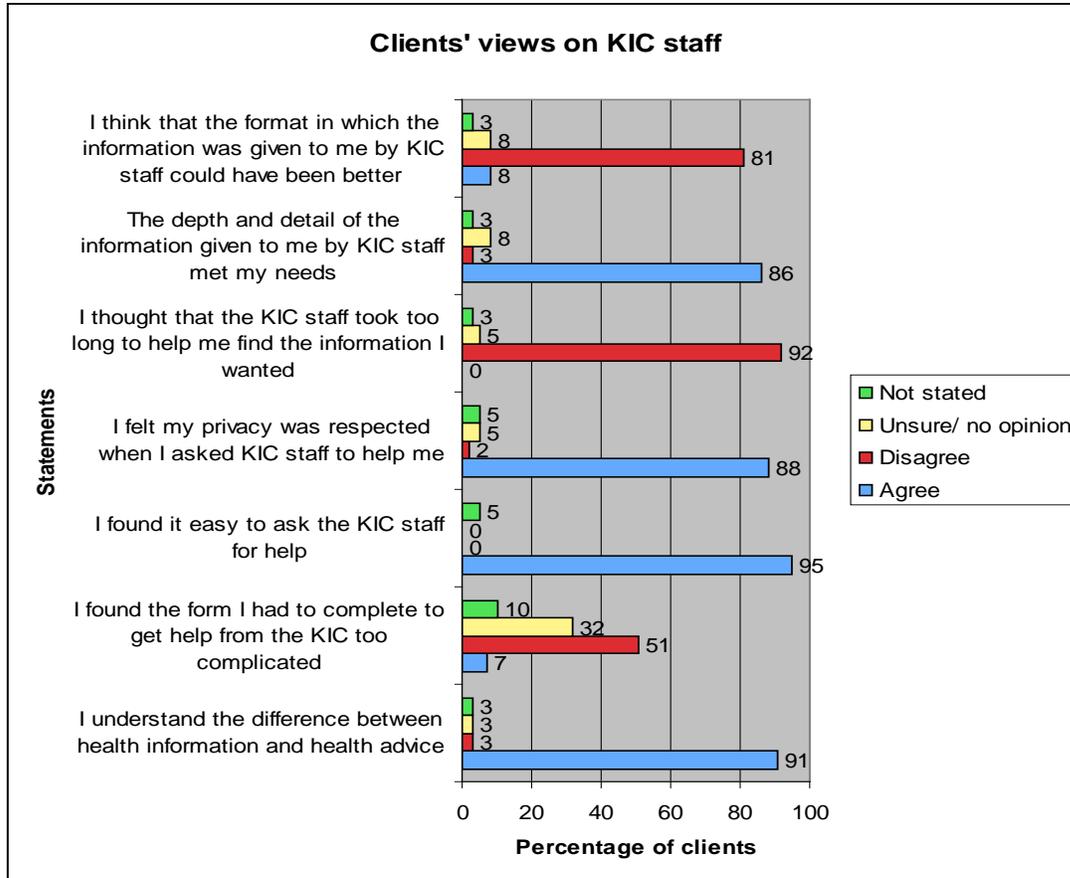


Figure 17: Clients' views on the KIC staff

From the chart above we can see that **the majority of respondents (91%) knew the difference between health information and health advice. This suggests that the KIC staff are effective in communicating this difference.** Indeed this was reflected by two interviewees who stated:

She was not able to offer any clinical explanation, advice about it because that obviously was not her role. But it just told me what I wanted to know to be able to ask some more intelligent questions when I did get hold of a medical person (KIC D)

They didn't give me knowledge they gave me the information. They didn't tell me this is how it is or that is how it is they just put me onto the right sites and right kinds of sources of information, which is very important I think. (KIC F)

Additionally **KIC was not seen as a place that should provide all the information but a useful resource to help in the first instance**

Now I look at the KIC not as something that will give all my answers, it's more a starting point isn't it? (KIC F)

Going back to the chart above we can see that **51% did not feel that the forms were too complicated**. However 32% were unsure or had no opinion on this statement. From some of the free text comments on the questionnaires it seems that many clients did not complete a form in the first place; rather a member of KIC staff did this on their behalf. **All of the questionnaire respondents found the KIC staff easy to approach.**

89% of respondents felt that their privacy was respected when they asked KIC staff for help. In the interview data a couple of participants indicated that they wanted a more private space to discuss issues with staff. These findings are reconciled by the fact that the questionnaire referred specifically to how a request for information was handled by staff. In interviews the issue of privacy referred to space and the possibility of other clients overhearing.

The majority of respondents felt that the time taken to provide information was acceptable (92%), that the level of detail and depth of information provided was acceptable to meet their needs (86%) and that the information provided was in an appropriate and acceptable format (81%).

4.10 Quality of information provided by staff

Interview participants remarked on the good quality of the service and information they received:

I: Did you have confidence in it [the information] in terms of its authority?

P: Yes I did. Partly because it was information that was given in a hospital information setting and also – I'm looking at the thing that's been printed out at the moment – and the website it's called labtestsonline and it says that it's a public resource on clinical lab testing from the laboratory professionals who do the testing. So it made me feel comfortable with it... It also of course, as she's printed it out, gives me the ability to know that this website exists and be able, maybe, you know, if I needed to, to consult it again in my own way (KIC D)

P: The depth of the information and it was really rapid, she got it. There was something she had to go off and research, she got it to be me the next day. I had it... Yes rapid and thorough is exactly what I wanted. She got me the information and then she also got me information on other experts to call for this meningitis helpline. And I called it, so it was useful information. I was able to follow up and it was perfect. I couldn't have asked for more. I was so, I was so grateful... It was really compassionate as well.

I: In what way was it compassionate?

P: Well it was like her tone of voice was like, you know 'oh I'm ever so sorry your friend has this', it was really personal, it was really compassionate and very genuine... This wasn't a computer library voice activated system thing. This was, this was very human and I really appreciated it (KIC K)

From participant K above we can see that **it was not just the provision of high quality information that was impressive but also the personal approach to the service; being dealt with sensitively at a time of stress and need.** This mirrors the comments of other interviewees who also spoke about KIC staff being prepared to put themselves out and help them. This was much appreciated especially by those who felt they were not given adequate time by doctors or other professionals or who felt the NHS had let them down:

You know, one of the hardest things for anybody to do is to walk in and ask somebody, a complete stranger, advice about anything. And they [KIC staff] just didn't make you feel uncomfortable... Their whole approach was very, very friendly... They weren't judgemental in any shape or form (KIC J)

P: She was very sympathetic and said that in fact, if I wanted to sort of write something up, they they could help with that as well.

I: Write what up sorry?

P: I was a bit fed up with, that they [the health professionals at the specific outpatient clinic the participant had attended] didn't give me enough information, but there's no point in just, just complaining... so, what I thought was, to actually write up, I'd written some sort of rough notes already to write up my experiences of the operation and send it off to the consultants and say, look this is my, you know, why can't you create a better leaflet for people who come in the future... She said there were, there were staff able to help with that as well (KIC I)

Staff at the KIC also took the time to help people understand different processes in the hospital and these were valued by interview participants:

Lots of times I use their services to find out about medical reasons for relatives as well as myself and they was actually able to tell me about the complaints procedures as well (KIC C)

As a result of what happened to me I wanted to find out what had gone wrong, and I needed to go onto the intranet and see the protocol and guidelines for the operation that I had and the lady at KIC did a great deal of work. She went to XXX to get information for me and so I can't fault them (KIC B)

4.11 Accessing information at the KIC

Following on in the baseline/ experience questionnaire we asked participants to indicate their agreement with a number of statements about the KIC (see chart below).

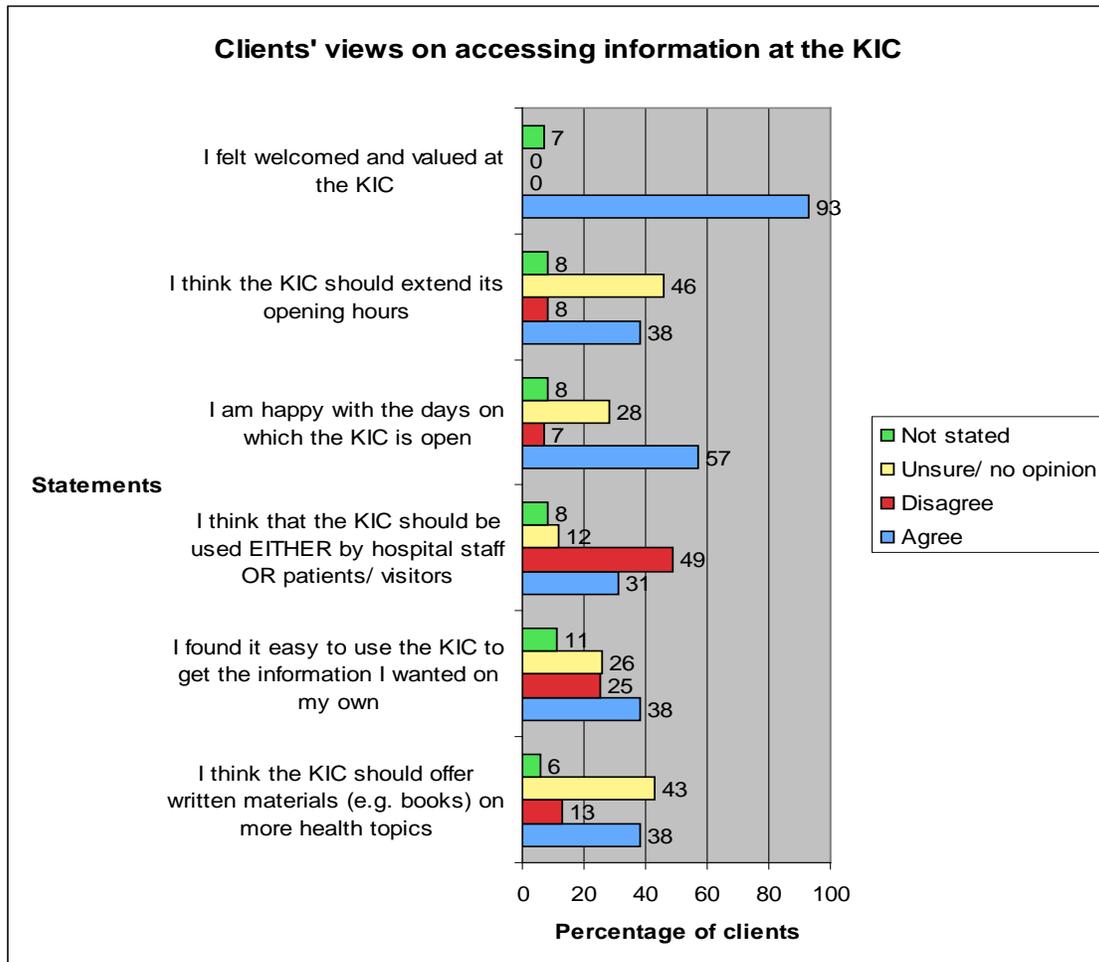


Figure 18: Clients' views on accessing information at the KIC

The figures in the above chart tell us that:

- **More clients than not (38% compared to 13%) wanted more written material on more health issues.** This could reflect an aspect of our sample; perhaps many were not IT confident or literate or preferred not to use computers and therefore wanted to access printed materials. **However 43% of respondents were unsure or had no opinion on this issue.**
- **Although the majority of respondents had asked KIC staff for help, interestingly 38% found it easy to access the information they**

wanted on their own. However it should be noted that 26% of respondents were unsure or had no opinion on this statement and 25% did not feel it was easy to access the information they wanted at KIC on their own. This needs to be taken into account.

- **The overwhelming majority of clients (93%) felt welcomed and valued at the KIC.**
- **More clients than not (49% compared to 31%) were happy with the KIC policy of allowing both staff and patients/ visitors to use the services offered.**
- **The majority of clients (57%) were happy with the days on which the KIC is open.** However 28% were unsure about this
- 46% were unsure if the KIC should extend its opening hours and **38% felt that the KIC should extend its opening hours.**

This final point about opening days and hours was discussed by some interviewees. Many indicated that they themselves had been able to access the KIC easily enough during its current opening times. However some people felt the present opening hours could be a problem for some people who work a traditional 9-5 week.

A thought for people who say, you know, say do standard office hours if they wanted to go in and access the information, they wouldn't be able to do so. Unless they could get to the hospital easily from where they worked, during their lunch break. So, you know, not being available say at a weekend (KIC D)

P: I think it's only open Monday to Friday isn't it?

I: Yeah, it is yeah.

P: Preferably if it's like someone who's working maybe and they're like doing like students and things like that maybe on a Saturday

...

P: It's just like when you've got working people if they need to gain access, if they don't have money for computers or whatever at home, if it would be viable it they would open on a Saturday (KIC C)

4.12 Usefulness of the KIC service

The findings for this section stem from both the baseline/ experience questionnaire data, and the interview data.

From the baseline/ experience questionnaire the overwhelming majority of participants (97%) found the KIC service to be useful. We asked questionnaire respondents to identify the useful aspects. These are presented in the chart below:

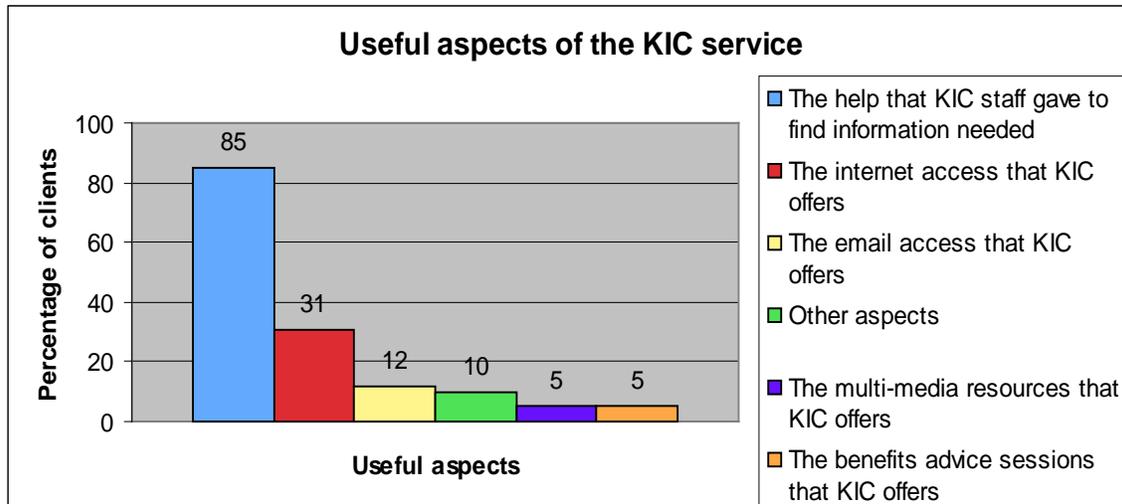


Figure 19: Useful aspects of the KIC service

As the chart above indicates the majority of participants felt that the help they received from the KIC staff to find information about a health issue was the most useful aspect of the KIC. The use of the internet was the second most useful service but this was reflected by only approximately one third of participants. It is interesting to note that multi-media resources and benefit advice sessions were viewed as useful by only a small proportion of people. One point to note here is that benefit advice sessions are available only once per week so may not be accessed by as many people. 6 people also indicated that they viewed other services as useful. These included:

- Other sources of information available at the KIC (N=2)
- Printed material (N=2)
- The fact that KIC staff sent a participant updated information (N=1)
- Peace and quiet and the helpful service (N=1)

35 respondents (97%) from the follow-up/ impact questionnaire felt that using the KIC had added positively to their experience of Guy's and St Thomas' Trust and we can therefore assume that the KIC adds significantly to their experience as a visitor at Guy's and St Thomas' NHS Foundation Trust.

However one interviewee highlighted **concerns that KIC services may be abused if they command no fee:**

I thought why are we getting all that free?... I'm not on the internet but I've observed the cost... a pound for an hour or something. That's not a great cost if you really want to use your internet, so getting it in here for free, I didn't expect that... If it's a rainy day and they happen to be in the vicinity or go into St Thomas' hospital you can have a quick sit down, you don't need to use the café or anything, go into the KIC, the television's on

all the time. That could be misused...' (KIC L)

The interviewee does not question the quality of the service but rather if it is really required or used appropriately to justify any cost. In reality the KIC does have small charges for some photocopying and other services. However access to high quality health information is an NHS priority and therefore it is important that this service, as with all other NHS services, is free at the point of use.

Section 5: Impact findings

In this section we discuss findings related to people's views on the impact that using the KIC has had on their lives and the lives of others. These data were captured in the follow-up/ impact questionnaire and in interviews. We begin with a general section and then move onto discuss understanding health issues, coming to terms with a disorder or condition, confidence and empowerment and wider benefits of the KIC.

From the questionnaire 34 people (94% of respondents) stated that the information they had received from the KIC helped them in some way. As part of the questionnaire we asked respondents to identify the ways in which the KIC information had helped them. These can be seen in the chart below:

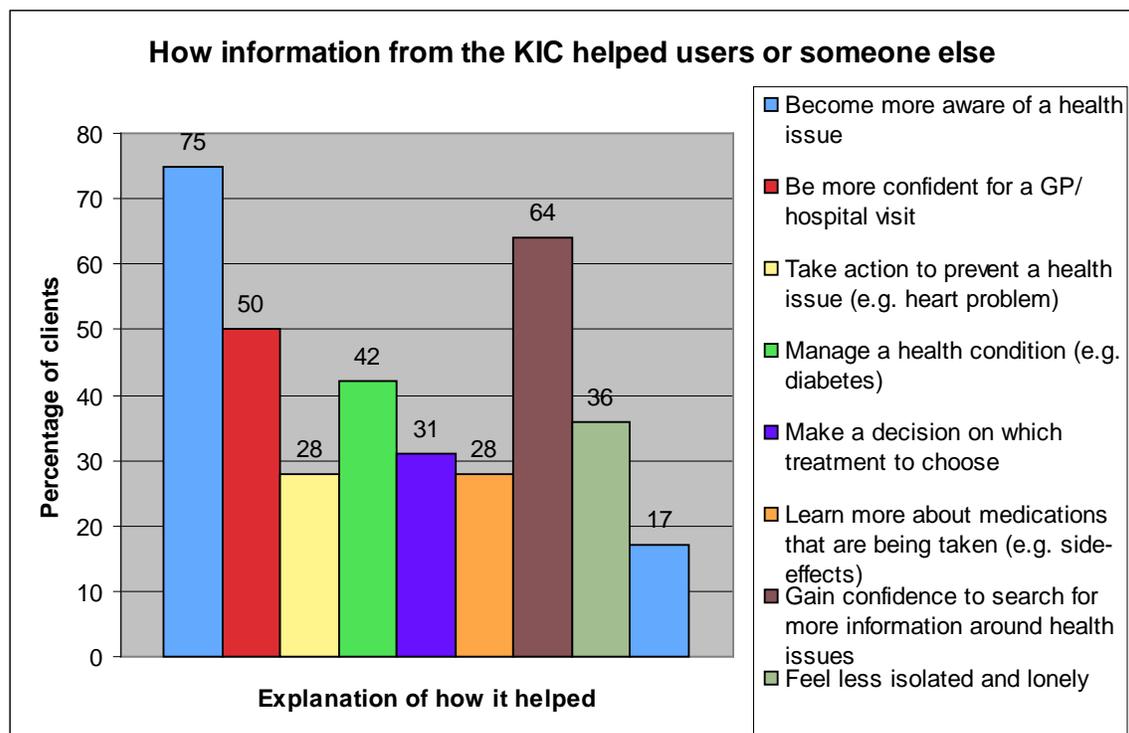


Figure 20: How information from the KIC helped users or someone else

5.1 Understanding health issues

As we can see from the chart above, raising awareness of a health issue was the single largest benefit outlined by questionnaire respondents. Prevention, management and understanding were also key aspects for questionnaire respondents. In the interview data participants spoke about the KIC information helping them understand an illness or disorder more. One participant who was diagnosed with migraine stated:

It helped me for the diet, you know, certain things what you're not supposed to eat and should get off it. It helped me to log things and then to actually find out what the triggers were that were causing it (KIC C)

Another respondent noted:

I wasn't aware that I had this disorder, it just brought a lot of things to light... It made me understand the fact that I was losing blood so much... who's had a bleeding problem most of her life and there's always been, you know, it's never been picked up on... but, do you know when you're unsure about something and ultimately things come together and you think 'ah, yeah, that's why this is happening, that's why I bruise so easily', well actually this is why you know? (KIC J)

As we can see in participant J's talk above the information allowed her to make sense of her medical history and to contextualise her experiences.

5.2 Coming to terms with a disorder or health condition

On balance participants preferred to know 'the worst' and felt that the information helped them come to terms with the situation. However, sometimes the information provided was initially frightening as it brought home the reality of the illness or raised awareness of the long term nature of the condition.

It was very close to when they said that I probably won't get better and I more than likely will have this for the rest of my life, so having that news and reading about it sort of emphasised that part, that I would not be able to recover fully and have a normal life like I used to. I suppose dealing with that yeah can be quite difficult, but I suppose it brings it home and you're not in denial anymore so it means you have to get to grips with and deal with it (KIC G)

I did find it frightening to think about the worst case scenario but I was also grateful to know what the worst case scenario could be (KIC K)

I: Did it make you unduly worried or anything like that?

P: I mean there is that element of it, yes. The more you learn the more you realise, the more you realise that there are, you know, consequences, and maybe that's why some of the consultants don't give you enough information. But I'm the sort of person that I do

want that kind of information.

I: So it didn't make you worried or anything like that?

P: I was worried yes, but I would have been worried anyway.

I: But the information didn't specifically make you worried?

P: No, no, I mean, I'd prefer to have as much information as possible so you can actually make an informed decision rather than kind of just be afraid. (KIC I)

5.3 Gaining confidence and increasing empowerment

Gaining confidence around dealing with health professionals and confidence around searching for health information were also reported by questionnaire respondents, 18 (50%) and 23 (64%) of people respectively.

Increased confidence can be linked to empowerment and this was identified in more depth in the interview data.

Firstly, people spoke of gaining confidence in dealing with health professionals, asking the right questions and making decisions about their health care:

It was very helpful because at the bottom in one of the articles that I got was a list of questions that you ask the doctor, and when I put these questions to the doctor firstly he tried to fob me off on some of them and he was not direct and forthcoming and I knew then it was time to see another doctor... Now those questions that I asked him, I would never have thought of some of them (KIC B)

I was able to go back with my own GP and discuss things that were, you know, that was going on, and we could look at different ways of handling [this]... I've had horrendous periods for you know, thirty odd years and it was, I was able now to go back with this information, with my GP and look at another way of handling it (KIC J)

I think it probably did make me more confident. I think the fact that I've been misdiagnosed about 4 times my confidence wasn't very good (KIC A)

Secondly, participants described feeling empowered because a diagnosis and authoritative information legitimised their concerns:

It helped me to educate my workforce, the boss like that it's not just a normal headache it's more severe than what they think it is and like also that people with migraine have rights um and yes it is

classed as a disability (KIC C)

I've had this for like 14 years before I got a diagnosis and I was saying I'm photosensitive and nobody would believe me, but now I've actually got a print out of what the condition is it's helped also in the sense that I can get my message across that I do have a problem and that it's not all in my mind and it's not just sunburn it is an actual problem (KIC G)

Thirdly, participants described using KIC as the beginning of learning more about a health issue or condition. The information was viewed as a 'starting point' and some participants stated how they then felt empowered to look for more information. In addition two interviewees described using the information in relation to others' care:

My youngest daughter has had problems with bleeding and stuff, which that she needed to be tested, you know, it just sort of like, you know, it's really hard to explain, but it just made you look at the whole family and think, 'well hang on a minute, something's going on within in this' (KIC J)

What I done with my copy, because I know plenty of people that suffer with it and they don't know and we suffer from the same problem, I just photocopied mine and gave it to them (KIC C)

KIC information can therefore be seen as having an effect on a wider group of people than just those who access the service.

Overall the KIC plays a role in helping people gain confidence, legitimising health concerns and helping people become more health aware; beginning the journey of finding out about, and taking a more active role in, their health care.

In addition 17% of follow-up/ impact questionnaire respondents indicated that they had been helped to get in touch with a support group. This in turn could increase empowerment and is an interesting point as it illustrates that KIC has a signposting role and can help contribute to empowering users at a variety of different levels.

5.4 Social and other benefits of the KIC

It is also interesting that 36% of people who completed the follow-up/ impact questionnaire stated that using the **KIC had helped them become less isolated and less lonely**. Whilst not directly related to health, this can be viewed as a social benefit. We directly asked questionnaire respondents about the social

benefits they had experienced as a result of using the KIC. 42% felt they had enjoyed a social benefit as a result of using the KIC. Besides a reduction in isolation and loneliness, respondents identified two further social benefits: helping them meet new people (17%) and keeping in contact with friends and family via use of email (12%). However, these aspects were not elicited from the interview data.

Finally, we asked questionnaire respondents if they could identify any other benefits that were associated with using the KIC service. 44% identified other benefits. Not all are specific benefits as some respondents included simple positive comments about the service. These are all listed below for completeness but grouped for ease of reference:

Provided reassurance and helped people prepare for a health procedure

- Allayed concerns about health condition (N=1)
- Eased my mind (knowing KIC is there) (N=1)
- Helped prepare information for an intervention (N=1)

Information provision and knowledge development

- KIC is a good source of helpful information (N=4)
- Improved knowledge of a specific condition (N=3)
- Electronic kiosk is a good source of information (N=1)
- Improved general knowledge about different conditions (N=1)

Provided welcome facilities

- Somewhere to relax (e.g. watch TV, read a newspaper) (N=2)
- Use of photocopying facilities was helpful (N=1)

Helped them deal with health professionals

- Improved productivity of the doctor/ patient relationship (N=1)

Of the follow-up/ impact questionnaire respondents 92% felt that the KIC had only produced positive benefits. When asked if using the KIC had produced any negative effect only 1 respondent identified an issue. However this was not actually a negative effect but, rather, a comment that a KIC member of staff had not been friendly when providing information when the client had visited the KIC for a second time.

Therefore **we feel confident in being able to say that using the KIC has a range of positive benefits on users.**

Section 6: Suggestions for improvement

The evaluation was keen to identify areas and ideas for improvements. In the baseline/ experience questionnaire 33% of respondents stated that they would make some changes to the KIC if given the chance. These are detailed by theme in the following sections below and supported by suggestions from interviews. In particular we discuss possibilities for extending KIC services and increasing the material at the KIC and improving service delivery.

6.1 Extending services at the KIC

Eleven comments were received on the follow-up/ impact questionnaires that related to improvements to the KIC facilities. These are grouped by theme:

Improved computing facilities

- Increase number of computers (N=2);
- Provide a printing facility for computers (charge for this) (N=1);
- More online services (N=1).

Improved environment and other facilities

- Increase the space (N=2);
- Increase the number of tables for reading/ writing (N=1);
- Make KIC quieter (N=1);
- Bigger space and tea/ coffee facilities (N=1);
- Make the computer chairs more comfy and adjustable (N=1).

Increased access and support

- Open longer (N=2);
- Expand the number of staff (N=1).

Interviewees made few requests for changes that related to the KIC environment. One suggested a chair by the kiosk outside the KIC and one suggested a separate TV room for people to watch TV properly if they wish. However 4 suggestions were made that could improve KIC accessibility and use by the client group. Firstly one participant **reaffirmed previous comments about extending or improving the opening hours and increasing the KIC space:**

I think maybe because of the volume of numbers that people actually use it because it was quite full when I went there. It was in lunchtime. Maybe they could do with a bigger room (KIC C)

Possibly opening on a Saturday (KIC C)

The two further comments suggested **developing an outreach service for KIC and checking whether clients' have any disability or accessibility issues before providing information:**

Maybe if the staff ask if you've got any disability... you go in there and they don't know whether you've got dyslexia or whatever and so maybe a tape of something... if you provide it on a tape or CD then you can store it (KIC C)

If occasionally people from KIC went up to wards because when you're up in the ward you don't feel very well and it's too much trouble or too much effort... If occasionally there was a facility so that they could come up to see you in the ward and say to you 'well I can get that information for you' (KIC B)

In addition one interviewee thought that not having good English could restrict access to some people so maybe **staff could direct people towards appropriate translation services or be able to access these** if needed. These suggestions could mean increased use by the target user group.

In addition to these issues the most frequently made comment around accessibility related to **the need to improve KIC publicity:**

I think it should be maybe publicised... maybe on the hospital radio stuff like for friends and family... people should be made more aware that this service is there and how to use it (KIC J)

It just needs to be more widely advertised and made known. It's such a good service (KIC K)

Obviously outside of the clinics they have notice boards. Well they may have had a poster up there but I don't think it's probably big enough. It's got to be something that takes the eye, that you know people are going to pick up on quickly (KIC G)

Probably a little more publicity outside would help (KIC F)

I'm not generally sort of, how can I put this, a nosey person, so I wouldn't walk past something like that and think 'ooh I wonder what's in there' and go in and automatically have a look... it does say it's a Knowledge and Information Centre but that, you know, might not mean anything to you... it doesn't sort of... sell itself... You know, its not sort of waving a banner and saying 'come in here and we'll tell you what you need to know' (KIC D)

A KIC leaflet could be there in the outpatient department or even

as part of a pack that's given to somebody who's about to have surgery. So, you could have a kind of information pack given to you... tailor-made to your particular... But then you could have general information leaflets, which includes you know, the KIC and patients sort of services really. (KIC I)

In addition **one person mentioned that more could be made of the website as a vehicle to publicise and provide KIC services.**

Finally on the follow-up/ impact questionnaire some suggestions were made about **expanding the KIC model to other sites:**

- KIC could act as a lobby for health care professionals (N=1)
- Expand to other hospitals (N=1)
- Encourage KIC to spread across the country (N=1)

6.2 Improving the material available

On the follow-up/ impact questionnaires 5 comments were received relating to potential improvements that could be made to the material that KIC provides or allows clients to access:

- Increase material on alternative medicine/ therapy (e.g. self healing) (N=1)
- More leaflets to take away (N=1)
- Increase the material (N=1)
- Allow patients access to the GSTT intranet (N=1)
- Improve the website (N=1)

These comments were somewhat reinforced through the interviews. One participant wanted **more information to take away:**

Ideally I'd have liked stuff that would be more ready to take away... I was going to stop and look up stuff on asthma and there was nothing I could really easily take away (KIC K)

Three participants commented that **the range of information could be improved with lay health focussed magazines or information that was summarised more concisely:**

One thing I found lacking was the lay person's medical magazines... I know the Lancet is more advanced but you know like Psychologies. Other journals which talk about medical issues you know in a more lay person kind of way (KIC F)

P: What given to me was a report... sort of a kind of medical trial

I think it was... Then I think another further link just went through the procedure... I'm fairly literate [but] I could imagine that some people would find that quite difficult to kind of digest.

I: So what would you suggest?

P: Just kind of into some kind of easily accessible chunks. You know... summarising the procedures but not leaving out detail. But making it in a much more accessible format really.

I: In what way more accessible?

P: You know, you could have frequently asked questions sort of and then answers and then what the procedure entails, what the after effects are... things like that. (KIC I)

In addition **one participant felt that some newer books were needed:**

What I do find is that the books are quite old, the editions... A think a little more modern stuff, more updated stuff (KIC F)

During the course of the evaluation stocks have indeed been updated and now an annual review of information and ordering system is in place to address this issue.

Finally, **one participant felt it would be helpful for patients to be able to access the protocols for interventions, treatments and procedures that are held on the GSTT internet:**

Would you be able to consider letting patients seeing the intranet? Because to be honest with you, the more information patients have the better it is because you can make informed decisions... like if I want to see the protocol for an operation it's probably on there, that's the sort of thing (KIC B)

6.3 Improving service delivery at the KIC

Whilst the comments regarding service delivery were very positive, some suggestions were made on the follow-up/ impact questionnaire about how these aspects could be improved:

- Prioritise use of computers for staff, then patients, no others (N=1)
- Slightly more privacy (N=1)
- Separate KIC from the voluntary service (PALS) (N=1)

This last comment is important to clarify. Firstly, PALS and the volunteer service are different services within the patient information team. Secondly, as previously mentioned in this report, the KIC merged with these two other services during the

period of the evaluation. This should actually work to the benefit of patients as all focus is on placing the patient at the centre of their work.

In the interviews participants identified five areas where services could be improved. Firstly, one participant suggested that **a telephone service would be useful**:

If they had somebody to man the phone for people that actually came away from there... or if they didn't have time and they wanted to go in there or they weren't open, if there was somebody that actually was on a phone that could send out literature to them... that would be beneficial I would have thought. I don't know whether they have that or not. (KIC G)

Secondly, one participant suggested that the **benefits service could be improved**, as it had not been accessible when he had tried to use it:

I asked about the DSS and benefits and there was a person that I was given a number for basically and I phoned up and it was just constantly ringing and basically nobody answering so... and I think she is only available on Thursdays. It would be good to have more information (KIC G)

Thirdly, mirroring a comment on the questionnaire, one participant suggested that **the inclusion of the PALS (Patient Advice and Liaison Service) within the KIC space was problematic**. He suggested the nature of the KIC had changed and brought negative aspects to the centre:

The whole set up has changed because of PALS and volunteers and KIC have all come together... and because of that there's a shortage of staff... they may not say they are pressurised but you can see the pressure... People come to complain now for PALS. There are lots of people who are very harassed and very hurried and they want to say things... (KIC F)

He went on to say that the **lack of privacy was also an issue** meaning that some clients may feel unable to discuss health concerns with a member of staff:

Even if I have something to say I don't say it because I don't want to say it in the open air (KIC F)

Finally, one participant suggested that **KIC could train or support some people to use the internet**. This relates to previous comments made that some users' are unable to use computers:

I don't know how it would work or whether it would work,

whether there are people who are interested in learning how to use the internet... they could have volunteers do that... There are people who are otherwise very alive and alert who want to know about life so you think it's a pity that they're missing out on all that (KIC F)

By providing training or support to users to use IT facilities and services the KIC could contribute to additional patient empowerment and improve people's wider skills.

6.4 The KIC staff

Whilst comments regarding KIC staff were overwhelmingly positive in the evaluation, some suggestions were made regarding problems or improvements that could be made. Firstly, **one interview participant indicated that they had had a mixed experience when dealing with KIC staff.** On some occasions the staff were excellent, on others not so good:

As I say the first person was brilliant but the second two were quite distant and didn't make me feel terribly comfortable... I think you need somebody a bit more patient... somebody perhaps more mature, I think they were quite... they may have been quite young people... (KIC G)

Such comments were in the minority and on reflection it seems likely that such experiences may relate to the reorganisation of services where new staff members joined the team and where there was a period of settling in for new members.

Another participant felt that it would be **good to have more volunteers** (N=1 in the follow-up/ impact questionnaire) or to increase the range of staff available. It was also suggested it might be good to **have someone independent, but clinically knowledgeable, who could go through information found by KIC staff** with clients:

In an ideal world it would be lovely to have somebody there that you could sit down with and talk through it with, you know, once you've got all the information and then may be somebody who understands... (KIC J)

6.5 Improving patient information

Some interview participants suggested that one **potential area of expansion to the KIC would be for the KIC staff to work proactively with clinical staff to**

create better patient information on procedures or interventions or to act as an intermediary between doctors and patients. Some participants felt that the medical professionals they encountered did not have time to talk to them about their illness or health concern so a development such as this could be beneficial in improving the doctor patient relationship and also ensuring patients are as informed as possible. This could lead to increased patient empowerment:

They [doctors] could count on KIC as a partner in educating the clients... Because I imagine it's hard for a doctor to explain about what a heart attack means over and over and over and over and over again... it could be much more of a partnership and the services [clinical services] could be overall improved.
(KIC K)

One interviewee was given some poor quality information by his clinic about the intervention he was going to receive. KIC could work with outpatients departments to create better information for patients:

You get information on foot operations... various specialists, further specialist information... they could obviously produce much better information. So, if KIC has the resources available to... research, find and create leaflets then that obviously would be helpful (KIC I)

All the suggestions for improvements made by participants were discussed at the Steering Group meetings. Many of the suggestions inform the recommendations of this report.

Section 7: Conclusions

This section illustrates the conclusions we have drawn from the evaluation of the KIC. These are grouped into themes.

7.1 The KIC environment and accessibility

- Most people found the KIC in passing but some were referred by health professionals.
- Some people were not clear what the KIC was at first. The name 'Knowledge and Information Centre' does not necessarily convey KIC's function. Some people compared the KIC to a library. This likeness was viewed positively.
- First impressions of the KIC were resoundingly positive
- Generally people felt that the KIC was easy to find. However some did not and many felt that the KIC was not well publicised.
- KIC facilities were seen as physically accessible to those with disabilities. However the focus on the provision of written media could exclude those with visual impairments or learning difficulties from accessing the full KIC services. Those with poor English skills may also be at a disadvantage.
- The KIC environment was viewed positively as professional, spacious, comfortable and as offering a personal touch. A couple of people suggested having separate room for the television. One person felt a chair by the kiosk outside the KIC would be useful. Some suggested that the KIC may need larger premises and some felt that having a private space to raise health queries would be beneficial.
- People were happy with the policy of allowing staff, patients and visitors to use the KIC service. However one individual commented that he was concerned that the service could be abused or misused as there is no fee for the service.
- Most people were generally happy with the opening days and hours but raised concern that the KIC would not be accessible to those who worked a traditional 9am – 5pm week.
- Only one person mentioned the KIC website and they felt this could be improved. This may indicate that the KIC's website is not being utilised to

its full potential.

7.2 The KIC staff

- The KIC staff were viewed by the vast majority of people as being supportive and happy to help clients. They were praised for often going 'above and beyond' expectations. They were generally seen as professional, friendly and respectful of people's privacy. On two occasions clients felt that staff were not approachable, possibly because they were busy or under pressure. These clients reiterated the need for staff to appear willing to help in all circumstances. These comments were however in the minority.
- The KIC staff communicated the difference between health information and health advice. People understood that it was not the job of the KIC staff to advise them on their health condition or situation. However some people would like access to an individual who could help them make sense of the information.
- Staff can help improve patient information provided by other services and departments. They can also provide support to patients who wish to contribute to information leaflets.
- Staff were seen to be compassionate and sensitive to individuals' circumstances and took time to help clients understand other related hospital processes or help them find additional sources of support. This was especially valued as many people who accessed the KIC service did so in a time of need, uncertainty, upset or stress.
- People overwhelmingly felt welcomed and valued at the KIC.
- KIC staff are vital to the success of the KIC. Their help and support was the most useful aspect of the service for the majority of people.

7.3 Health Information provided by the KIC

- The majority of people used the KIC to access information on a health condition, treatment, intervention or procedure.
- Many people stated that they could easily find the information they needed on their own. However many also asked the KIC staff for help to find the information they required because they were unable to find it on their own. Some people were unable to search the printed material and some found

the amount of material overwhelming. The majority of people who needed help indicated that the crucial barrier for them was being unable to use a computer or the internet.

- Information provided by the KIC staff was sufficient in depth and quality. It generally met clients' needs. It was also viewed by the majority as readable and easy to understand. However some expressed concern that some information may be hard for some people with lower levels of education or learning difficulties to comprehend.
- People were impressed by the quality of the information and the speed with which it was provided.
- Some people felt that a greater range of information should be provided and that there should be more information available to take away.

7.4 The impact KIC has on clients

- The KIC has clear positive impact on clients, is viewed as being useful by those who use it and is seen as an asset to Guy's and St Thomas' NHS Foundation Trust.
- The biggest impact KIC has is helping people understand health issues.
- Generally people preferred to have as much information as possible and to know the 'worst case scenario'. This helped them come to terms with the situation. However, some people said that the information provided by the KIC was initially frightening as it brought home the reality of their condition.
- Information from the KIC helped people gain confidence when dealing with health professionals and when searching for further health information. More specifically once they had the information from the KIC some said they were able to ask the right questions of health professionals. KIC information can be seen as contributing positively to the doctor/ patient relationship.
- The KIC information was viewed as authoritative and from a reputable source. The information helped to legitimise individuals' health concerns. Such legitimisation was seen as empowering.
- People did not expect the KIC information to provide all the answers they needed. Rather the information was seen as a starting point for learning more.

- People reported passing information provided by the KIC onto others who they thought would also benefit from it. Therefore the benefits of the KIC are not restricted to those who just access it directly.
- People reported social benefits of using KIC as well as those related to health information and confidence. For example, some said they experienced a reduction in their isolation and loneliness as a result of visiting the KIC, some had met new people and some found it easier to keep in touch with friends and family through email.

7.5 Suggestions for improvement

- Many people made suggestions regarding potential improvements that could be made to the KIC service. In general people felt that the expansion of the KIC should be pursued. Expansion related to the physical space, increased materials, increased opening hours, access at other sites and increasing the KIC remit to include lobbying for patients and health professionals. Particular examples are provided below:
 - Provision of an outreach service so that KIC staff can visit patients who are unable to leave the wards.
 - Expansion of the KIC service to provide information by telephone and increase the benefits advice sessions on offer.
 - Provision of IT training for those unable to use computers or access health information online.
 - Development of collaborative work with clinics to develop better patient information material.
 - Charging for some services to stop these being abused.
 - Expansion of the KIC service to other health sites.

Section 8: Recommendations

This section makes a number of recommendations based on the findings and conclusions of the KIC evaluation. These recommendations have been presented to and discussed with the KIC management. We include responses to each recommendation to indicate which recommendations can be implemented and how improvements can be made.

8.1 The KIC environment

- Consideration should be given to extending opening hours into an evening or a Saturday morning to enable more people to access the service.

Response: In a context of limited resources and as a cross-site service, our priority must be to focus on trying to ensure parity of provision for patients at the Guy's site and establishing a patient information service there. Only then can we explore the possibility of extending opening hours.

- Consideration should be given to providing private space that can be used if individuals prefer to raise a health concern or issue confidentially.

Response: Space is limited within the Trust, however we are aware this is a concern for users and are happy to explore solutions to this.

- A chair should be sited outside the KIC main door by the kiosk for people who wish to use this but cannot stand for long periods of time.

Response: Due to Health and Safety considerations it is not possible to have a chair next to the kiosk outside the KIC. The kiosk is due to be replaced in the coming year and the newer models are much lower, making them more accessible to wheelchair users and younger people.

- A publicity strategy for the KIC should be developed and this should include providing improved and increased signage within St Thomas' Hospital, leaflets placed in hospital clinics, departments and wards, posters on notice boards and possibly advertisements on the hospital radio. Consideration should be given to publicising the KIC service in local GP surgeries or other health venues. However it is recognised that any increased demand needs to be predicted and deemed manageable prior to this action.

Response: New publicity about the service is in production; however we

are aware of the need to market the service on an on-going basis. Over the next year we will be developing a patient information strategy which will include an internal and external marketing strategy for the patient information service in the KIC.

- Consideration should be given to expanding the media in which information is provided by the KIC. For example information on CD might be more useful to those with visual impairment or learning difficulties such as dyslexia.

Response: We do carry information in a range of formats including CD, DVD, easy-read and audio-tape. The fact that participants were not aware of this suggests that existence of these resources should be highlighted in the marketing of the service.

- Translation and interpretation services could be accessible for those with poor English skills.

Response: We have recently created folders of health information material in languages other than English and also work closely with the Language Support Department to arrange interpreters or translate materials as required. This needs to be reflected in marketing and publicity activities.

- Consideration should be given to whether the potential of the KIC website is being realised and whether this could act as a portal to more health information.

Response: The patient information section of the KIC website does act as a portal to sites of quality checked health information and support groups. Again, the fact that respondents were unaware of this suggests that marketing of this resource is key.

8.2 KIC staff

- Consideration should be given to having more volunteers and possibly providing clients with access to an independent individual who is able to discuss health advice or concerns with them in more detail.

Response: We intend to re-visit customer care skills in future staff training session to ensure that staff feel supported and able to deal with pressure during busy times. We will also consider further use of volunteers to support KIC staff during busy periods.

We will also explore the possibility of sign posting patients to health advocates or health trainers to support them in using the information that

they obtain.

8.3 Health information provided by the KIC

- Consideration should be given to increasing the range of material that is available in the KIC. Some suggestions included having newer editions of books, subscribing to a few key lay health and wellbeing publications (for example, Psychologies), displaying more leaflets for more health conditions and making local health/ treatment protocols available.

Response: There is a regular programme of updating stock which had been completed for 2007/08 at the end of the research project. Currently we carry information on over 90 individual health conditions and space is limited. We feel it would be important to enhance the accessibility of the existing stock before considering expanding the number of conditions covered.

- Consideration should be given to checking that all information provided to clients is at a level that they can understand.

Response: We will re-visit issues of gauging the level of information required by service users and issues of information accessibility during a staff training session.

- Consideration should be given to asking clients what additional material they would like to see available in the KIC. This could possibly be done via a short form at the reception desk.

Response: We will introduce a "suggestions slip" to enable patients and relatives to make suggestions for materials they would like to see stocked by the patient information service.

8.4 The impact KIC has on clients

- The KIC should continue to help people make the most of the information they obtain from the KIC and encourage them to discuss this with their health professionals as necessary.

Response: Together with the KIC User group a list of "Questions to ask your doctor" is being developed to help patients make the most of the information they obtain and encourage them to discuss concerns with their health care professional. We will emphasis the importance of KIC staff encouraging patients to discuss any concerns they have with their healthcare professional in a future staff training session.

- The KIC staff should be aware that information provided could cause upset or anxiety and consideration should be given to direct people to local support or counselling services as necessary. Potentially staff may need to be offered training to help them cope with upset or anxious individuals.

Response: Via staff training we will encourage staff to offer patients details of a support group every time they provide health information to users of the service.

- The social benefits of using the KIC should not be underestimated and should be balanced with the provision of health information.

Response: We will ensure the social benefits of the KIC are reflected in all publicity materials and marketing strategies.

- The KIC is seen very positively by users of the service in helping them understand health issues and empowering them to seek further information themselves. The role of KIC in helping integrate information into patient care should be promoted more widely to staff.

Response: The importance of integrating information into patient care and the role of the KIC in supporting this will be explored in the forthcoming patient information strategy through initiatives such as information prescriptions and patient information pathways.

- Clients who used the KIC view the service positively and felt it reflects positively on their experience of the Trust as a whole. The KIC should be promoted as one of the services which can add positively to patient's experience of being treated at the Trust.

Response: We will ensure that staff in the wider organisation are aware of the positive contribution of the KIC to the wider patient experience and that the benefits of the patient information service within the KIC are included in promotional materials about the Trust.

8.5 Suggestions for improvements

- Consideration should be given to working more closely with outpatient departments, clinics and inpatient wards within St Thomas' to improve the information available to patients and visitors throughout St Thomas'. KIC was recognised as having particular and special skills that could help clinicians or managers design information leaflets and help the hospital produce information packs.

Response: The Trust has recently developed an information policy which designates the KIC the role of supporting staff in identifying good quality externally produced information leaflets to use with patients and identifying research to support them in developing their own materials.

- Consideration should be given to whether a regular time could be devoted by the KIC staff to visiting the wards or outpatient departments to see if patients have any health information needs.

Response: We will explore the possibility of providing information outreach to the wards and extending the information prescription initiative to additional outpatient clinics.

- Consideration should be given to whether the benefits advice sessions can be increased and whether more information can be provided by telephone.

Response: This service is being provided by an external agency and is under threat due to resource pressures. We will explore other options and identify services we can signpost clients on to.

- Information about how the KIC service is funded could be displayed to make it clear to clients that the KIC is not funded to the detriment of patient care. In addition if demand increases vastly then charging for some services could be introduced, e.g. use of email or photocopying more than a specific number of pages.

Response: Originally funded by Charity money, the KIC funding has now been mainstreamed by the Trust in the light of the increasing number of national policy initiatives patient empowerment and public involvement.

- Consideration should be given to whether the KIC should offer training in key areas related to health information or patient empowerment.

Response: We are keen to explore provision of training for patients in these areas.

- The KIC should send information on its service to other NHS trusts in order to share its good practice around providing health information and improving patient empowerment.

Response: As part of the marketing strategy we will look at ways of sharing information about the KIC model of information provision with other colleagues in the health information sector and NHS.

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Appendix One: A copy of the baseline questionnaire

Please note that the formatting has been slightly modified.

About your use of KIC services

Please feel free to tick **MORE** than one option for the following question

1. My reasons for using the KIC were:	
¹ <input type="checkbox"/>	To use the KIC's printed material (e.g. books) to find out about health issues (e.g. a medical condition)
² <input type="checkbox"/>	To use the KIC's electronic facilities (e.g. internet) to find out more about health issues (e.g. a medical condition)
³ <input type="checkbox"/>	To ask a KIC member of staff to help me find information about health issues (e.g. a medical condition)
⁴ <input type="checkbox"/>	To use the internet/ email facilities that KIC offers for non-health related reasons
⁵ <input type="checkbox"/>	To use the benefits advice sessions
⁶ <input type="checkbox"/>	To use the photocopying/ printing facilities
⁷ <input type="checkbox"/>	To go somewhere I could relax
⁸ <input type="checkbox"/>	Other, please specify

Please tick only **ONE** option for the following question

2. I asked a KIC member of staff to help me find information because:	
¹ <input type="checkbox"/>	I was unable to use the electronic facilities available (e.g. the internet)
² <input type="checkbox"/>	I was unable to search the printed material (e.g. books)
³ <input type="checkbox"/>	I could not find the information I wanted using the printed material or the electronic facilities
⁴ <input type="checkbox"/>	I was asked to go to a KIC member of staff for help by a doctor, nurse or other healthcare professional
⁵ <input type="checkbox"/>	Other, please specify

Please tick only **ONE** option for the following question

3. I needed the information for:	
¹ <input type="checkbox"/>	Myself
² <input type="checkbox"/>	Friend(s)/ family/ partner
³ <input type="checkbox"/>	Myself AND friend(s)/ family/ partner

Please tick only **ONE** option for the following question

4. On how many occasions have you used the KIC?	
¹ <input type="checkbox"/>	Once
² <input type="checkbox"/>	2-3 occasions
³ <input type="checkbox"/>	4-5 occasions
³ <input type="checkbox"/>	6 or more occasions

Your experiences of KIC services in general

Please tick only **ONE** option for the following question

5. Did you find the KIC services useful?	
¹ <input type="checkbox"/>	Yes (go on to question 6 BEFORE moving on to question 7)
⁰ <input type="checkbox"/>	No (please give us your reasons below and go straight to question 7)
<p>If no, please tell us why you did not find the KIC services useful.</p>	

Please feel free to tick **MORE** than one option for the following question

6. I found the following KIC services useful:	
1 <input type="checkbox"/>	The multi-media resources that KIC offers (e.g. videos, DVDs, tapes)
2 <input type="checkbox"/>	The internet access that KIC offers
3 <input type="checkbox"/>	The email access that KIC offers
4 <input type="checkbox"/>	The benefits advice sessions that KIC offers
5 <input type="checkbox"/>	The help that KIC staff gave me to find the information I needed
6 <input type="checkbox"/>	Other, please specify

For **EVERY** statement, please tick the box that reflects your opinion

Statement	Strongly Agree	Agree	Disagree	Strongly Disagree	Not sure / No opinion
7. "I think that the KIC should offer written materials (e.g. books) on more health topics"	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
8. "I found it easy to use the KIC to get the information I wanted <u>on my own</u> "	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
9. " I think that the KIC should be used EITHER by hospital staff OR patients/visitors"	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
10. "I am happy with the DAYS on which the KIC is open"	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
11. "I think the KIC should extend its opening hours "	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
12. "I felt welcomed and valued at the KIC"	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>

Your experiences of the KIC staff and the process of asking for help

For **EVERY** statement, please tick the box that reflects your opinion

Statement	Strongly Agree	Agree	Disagree	Strongly Disagree	Not sure / No opinion
13. "The KIC was easy to find at St Thomas"	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
14. "I understand the difference between 'health information' and 'health advice'"	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
15. " I found the form I had to complete to get help from the KIC too complicated"	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
16. "I found it easy to ask the KIC staff for help"	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
17. "I felt that my privacy was respected when I asked KIC staff to help me"	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
18. "I thought that the KIC staff took too long to help me find the information I wanted"	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
19. "The depth and detail of the information given to me by KIC staff met my needs"	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
20. "I think that the format in which the information was given to me by KIC staff could have been better"	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>

Your experiences of the KIC environment and space

Please tick only **ONE** option for the following question

21. Do you have any difficulties, physical or otherwise, that may make it a challenge for you to use the KIC?

¹	<input type="checkbox"/>	Yes	If YES, please briefly describe these difficulties and how they make it a challenge for you to use the KIC?
⁰	<input type="checkbox"/>	No	

For **EVERY** statement, please tick the box that reflects your opinion

Statement	Strongly Agree	Agree	Disagree	Strongly Disagree	Not sure / No opinion
22. "I think the layout of the KIC space makes it feel too cramped"	¹ <input type="checkbox"/>	² <input type="checkbox"/>	³ <input type="checkbox"/>	⁴ <input type="checkbox"/>	⁵ <input type="checkbox"/>
23. "I enjoy coming to KIC"	¹ <input type="checkbox"/>	² <input type="checkbox"/>	³ <input type="checkbox"/>	⁴ <input type="checkbox"/>	⁵ <input type="checkbox"/>
24. "I think it is too noisy at KIC"	¹ <input type="checkbox"/>	² <input type="checkbox"/>	³ <input type="checkbox"/>	⁴ <input type="checkbox"/>	⁵ <input type="checkbox"/>
25. "I think that the atmosphere at the KIC is warm and inviting"	¹ <input type="checkbox"/>	² <input type="checkbox"/>	³ <input type="checkbox"/>	⁴ <input type="checkbox"/>	⁵ <input type="checkbox"/>

Would you change anything about the way in which KIC services are run?

26. If you were given a chance to run the KIC services, would there be ANYTHING you would do differently or change?

<input type="checkbox"/>	Yes
	If YES, please tell us what you would do differently and why.
<input type="checkbox"/>	No

About you

In this final section, we explore the most important person in our programme, you!
Please rest assured that ALL information will be kept confidential.

27. Are you:

1	<input type="checkbox"/>	Female
2	<input type="checkbox"/>	Male

28. What is your age?

1	<input type="checkbox"/>	16-24
2	<input type="checkbox"/>	25-44
3	<input type="checkbox"/>	45-64
4	<input type="checkbox"/>	65-74
5	<input type="checkbox"/>	75-84
6	<input type="checkbox"/>	85+

29. What is your ethnic group? Please choose ONE of the sections from A to F and then tick the most appropriate box to indicate your cultural background.

A. White	
1	<input type="checkbox"/> British
2	<input type="checkbox"/> Irish
3	<input type="checkbox"/> Other White background
	Please specify other

B. Mixed	
4	<input type="checkbox"/> White & Black Caribbean
5	<input type="checkbox"/> White & Black African
6	<input type="checkbox"/> White & Asian
7	<input type="checkbox"/> Other Mixed background
	Please specify other

C. Chinese or Other ethnic group	
8	<input type="checkbox"/> Chinese
9	<input type="checkbox"/> Other ethnic group

D. Asian or Asian British	
10	<input type="checkbox"/> Indian
11	<input type="checkbox"/> Pakistani
12	<input type="checkbox"/> Bangladeshi
13	<input type="checkbox"/> Other Asian background
	Please specify other

E. Black or Black British	
14	<input type="checkbox"/> Caribbean
15	<input type="checkbox"/> African
16	<input type="checkbox"/> Other Black background
	Please specify other

F. Not Stated	
17	<input type="checkbox"/> I do not want to state my cultural background

30. Is English your FIRST language?

¹ <input type="checkbox"/>	Yes
² <input type="checkbox"/>	No
	If no, please tell us what your first language is

31. Are you:

¹ <input type="checkbox"/>	A patient
² <input type="checkbox"/>	A visitor of a patient (friend/ relative/ partner)
³ <input type="checkbox"/>	A member of the staff at the Trust
⁴ <input type="checkbox"/>	Other, please specify

We are so grateful for your time today! Could you possibly consider completing one final questionnaire on how useful you found the information you received? If you could, a researcher from the university will contact you in a month's time to complete a very short questionnaire over the phone. If they can not contact you by phone, they will send you a questionnaire by post to complete. *The questionnaire will take no more than 10 minutes to complete.*

¹ <input type="checkbox"/>	Yes
² <input type="checkbox"/>	No

If you would like to take part in this further questionnaire work, **please give us your name and contact details below.**

Name:
Telephone number
Address
Date:

<input type="checkbox"/>	Please tick here if you would like a summary of the survey results when the study is completed
--------------------------	--

Thank you for completing this questionnaire
Any answers that you have given to us will remain confidential
Please fold this completed questionnaire and deposit it in the questionnaire box that has been provided at the KIC.

Appendix Two: A copy of the follow-up questionnaire

Please note that the formatting has been slightly modified.

About your use of KIC services

Please tick only **ONE** option for the following question

1. Do you still use the KIC?	
¹ <input type="checkbox"/>	Yes (go to question 2 and 3 BEFORE moving on to question 4)
⁰ <input type="checkbox"/>	No (go straight to question 4)

Please tick only **ONE** option for the following question

2. On how many occasions have you used the KIC in the last month?	
¹ <input type="checkbox"/>	Once
² <input type="checkbox"/>	2-3 occasions
³ <input type="checkbox"/>	4-5 occasions
³ <input type="checkbox"/>	6 or more occasions

Please feel free to tick **MORE** than one option for the following question

3. My reasons for using the KIC were:	
¹ <input type="checkbox"/>	To use the KIC's printed material (e.g. books) to find out about health issues (e.g. a medical condition)
² <input type="checkbox"/>	To use the KIC's electronic facilities (e.g. internet) to find out more about health issues (e.g. a medical condition)
³ <input type="checkbox"/>	To ask a KIC member of staff to help me find information about health issues (e.g. a medical condition)
⁴ <input type="checkbox"/>	To use the internet/ email facilities that KIC offers for non-health related reasons
⁵ <input type="checkbox"/>	To use the benefits advice sessions
⁶ <input type="checkbox"/>	To use the photocopying/ printing facilities
⁷ <input type="checkbox"/>	To go somewhere I could relax
⁸ <input type="checkbox"/>	Other, please specify.....

How using the KIC may have benefited you
Information-related benefits

Please tick only **ONE** option for the following question

4. Did the information you received from the KIC help you in anyway?	
1 <input type="checkbox"/>	Yes (go on to question 5 BEFORE moving on to question 6)
0 <input type="checkbox"/>	No (please give us your reasons below and go straight to question 6)
If no, please tell us why you did not find the information that you got from the KIC to be useful.	

Please feel free to tick **MORE** than one option for the following question

5. The information I got from the KIC helped me or someone else:	
1 <input type="checkbox"/>	Become more aware of a health issue
2 <input type="checkbox"/>	Be more confident for a GP/ hospital visit
3 <input type="checkbox"/>	Take action to prevent a health issue (e.g. heart problem)
4 <input type="checkbox"/>	Manage a health condition (e.g. diabetes)
5 <input type="checkbox"/>	Make a decision on which treatment to choose
6 <input type="checkbox"/>	To learn more about medications that are being taken (e.g. side-effects)
7 <input type="checkbox"/>	To gain confidence to search for more information around health issues
8 <input type="checkbox"/>	To feel less isolated and lonely
9 <input type="checkbox"/>	To get in touch with a support group
10 <input type="checkbox"/>	Other, please specify

Please tick only **ONE** option for the following question

6. Did the information you gained from using the KIC services or from KIC staff have any negative effects?

¹	<input type="checkbox"/>	Yes
If YES, please briefly describe these negative effects		
⁰	<input type="checkbox"/>	No

Conclusion

For the statement below, please tick the box that reflects your opinion

Statement	Strongly Agree	Agree	Disagree	Strongly Disagree	Not sure / No opinion
7. "I feel that the KIC added positively to my experience of Guy's & St Thomas' hospitals"	¹ <input type="checkbox"/>	² <input type="checkbox"/>	³ <input type="checkbox"/>	⁴ <input type="checkbox"/>	⁵ <input type="checkbox"/>

Please tick only **ONE** option for the following question

8. Did you experience any social benefits from using the KIC? (E.g. meeting new people etc...)

¹	<input type="checkbox"/>	Yes (go on to question 9 BEFORE moving on to question 10)
⁰	<input type="checkbox"/>	No (go straight to question 10)

Please feel free to tick **MORE** than one option for the following question

9. The KIC services helped me to:

¹	<input type="checkbox"/>	Keep in touch with family and friends (e.g. via email)
²	<input type="checkbox"/>	Meet new people
³	<input type="checkbox"/>	Feel less isolated
⁴	<input type="checkbox"/>	Other, please specify

10. Are there any other benefits that you feel you gained from using the KIC services? If so, please tell us below what these were.

We are so grateful for your time today! Would you like to take part in further interview work we are doing for this study? You will only be interviewed once. The interview can be done at a time and date of your choosing and can be done face-to-face in a local community venue or, if you prefer, over the phone. There is also the choice of doing the interview in a group of no more than 4 other individuals.

¹ <input type="checkbox"/>	Yes
² <input type="checkbox"/>	No

If you would like to take part in an interview, **please give us your contact details below (if these are different from the details we used to contact you already):**

Telephone number
Address

Thank you for completing this questionnaire
Any answers that you have given to us will remain confidential
Please seal this completed questionnaire in the pre-paid envelope (so no stamp is needed) provided and post it.

Appendix Three: A copy of the interview topic guide

Please note that the formatting has been slightly modified.

Area	Question	Prompt
Introduction	<ul style="list-style-type: none"> • Thank them for taking part • Assurances about confidentiality 	
Using the service [Ice breaker]	Please tell me a little bit about what made you use the KIC service in the first place?	<ul style="list-style-type: none"> • Mode of referral (self-referral, referred by health professional) • The reasons why they wanted to use the KIC service (concern about medical issue, internet etc...). • For whom they used the KIC service
Experiences	What were your impressions about the general facilities available at KIC?	<ul style="list-style-type: none"> • What did they think about the number of computers? • What did they think about the range of written material on display? (Sufficient range? Accessibly displayed?). • Were there enough places for them to get refreshments? • Was there anything missing?
	What were your impressions about the service given by the KIC staff ?	<ul style="list-style-type: none"> • Were they friendly/ warm? • Were they helpful? • Were they knowledgeable and efficient? • Did it take too long for you to get the information you requested?
	What did you think about the quality of the information that was given to you?	<ul style="list-style-type: none"> • Was the information readable/ comprehensible? (i.e. pitched at the right level) • Was the information accessible (i.e. legible – font, layout, appearance, visually appealing)? • Did the information address your question/ needs? • Did you have confidence in the information (e.g. was it from a credible source, based on sound research, was it up to date). • How would you have improved the quality of information given to you?
	What were your impressions about the	<ul style="list-style-type: none"> • Days and times of opening?

	accessibility of the KIC service?	<ul style="list-style-type: none"> Views on the accessibility of the service to those with physical disabilities?
	Was there anything about the way KIC services were run that you would change ?	<ul style="list-style-type: none"> If so, what and why?
Impact	Did the information you receive from the KIC make a difference to the way you lived your life in anyway?	<ul style="list-style-type: none"> Was it helpful/ useful? If so, why was it helpful? <ul style="list-style-type: none"> Help to understand what was wrong Realistic idea of outcome of illness Realistic idea of outcome of operation or treatment Helped identify support (sources of help, further information) Helped to provide reassurances Help others understand Legitimise help-seeking To whom was it helpful? If it wasn't helpful, why not?
	Did the information make a difference to what decisions you made about your health, self-care and/ or treatment ?	<ul style="list-style-type: none"> Helped self-care in any way Reach decisions about service provider Able to have a more fuller discussion with health professional/ challenge their views/ make most of consultation
	Did the information you receive from the KIC have any negative effects on you or a loved one?	<ul style="list-style-type: none"> E.g. made them hyper-concerned about a health issue.
	Did using the KIC service have any other effects on you that you did not anticipate ?	<ul style="list-style-type: none">
	Is there anything that could have been done to help make the information you received more useful to you ?	<ul style="list-style-type: none"> Someone to talk the information through with you Being referred to a support group/ health care professional or another patient to talk through the information with you.

Appendix 4: Demographic tables

Table 1: Demographic characteristics of participants who completed a baseline/ experience questionnaire

		Total	%
Gender	Female	40	66
	Male	19	31
	Not stated	2	3
Age	25-44	18	30
	45-64	27	44
	65-74	10	16
	75-84	5	8
	Not stated	1	2
Ethnicity	White British	35	58
	White Irish	2	3
	Other white	7	11
	Mixed	1	2
	Asian or Asian British	7	11
	Black or Black British	6	10
	Not stated	3	5
English as first language	Yes	52	86
	No	7	11
	Not stated	2	3
Type of client	Patient	28	46
	Visitor	13	21
	Staff	5	8
	Other	11	18
	Not stated	4	7

Table 2: Demographic characteristics of participants who completed a Follow-up/ impact questionnaire

		Total	%
Gender	Female	27	75
	Male	9	25
	Not stated	0	0
Age	25-44	10	28
	45-64	16	44
	65-74	8	22
	75-84	2	6
	Not stated	0	0

Ethnicity	White British	21	57
	White Irish	1	3
	Other white	5	14
	Mixed	1	3
	Asian or Asian British	5	14
	Black or Black British	2	6
	Not stated	1	3
English as first language	Yes	33	92
	No	3	8
	Not stated	0	0
Type of client	Patient	13	35
	Visitor	11	31
	Staff	2	6
	Other	8	22
	Not stated	2	6

Table 3: Demographic characteristics of interview participants

		Total	%
Gender	Female	13	72
	Male	5	28
	Not stated	0	0
Age	25-44	3	17
	45-64	10	55
	65-74	5	28
	75-84	0	0
	Not stated		
Ethnicity	White British	10	55
	White Irish	1	6
	Other white	3	16
	Mixed	1	6
	Asian or Asian British	2	11
	Black or Black British	1	6
	Not stated	0	0
English as first language	Yes	18	100
	No	0	0
	Not stated	0	0
Type of client	Patient	7	39
	Visitor	4	22
	Staff	1	6
	Other	4	22
	Not stated	2	11

As detailed in Section 3 above, due to the relatively small number of respondents who returned a questionnaire at the follow-up measurement time, it was not possible to determine whether or not there were any significant differences in the majority of the demographic characteristics between those that completed a questionnaire at the baseline measurement time and those that eventually returned a questionnaire at the follow-up measurement time. The only valid comparison that could be made between both measurement times concerned the variable 'gender'. This comparison indicated that there was no significant difference in terms of gender between respondents who completed the questionnaire at the baseline measurement time and those that had returned a questionnaire at the follow-up measurement time (Pearson Chi-squared 0.138; $p=0.05$).

Appendix Five: Baseline/ experience and follow-up/ impact questionnaire tables

Table 4: Clients' reasons for using the KIC

Why participants used the KIC	Number (and percentage) of clients
To ask a KIC member of staff to help them find information about a health issue	50 (82%)
To use the KIC's printed material to find out about health issues	27 (44%)
To use KIC's electronic facilities to find out more about health issues	15 (25%)
To go to the KIC just to relax	9 (15%)
To use the photocopying/ printing services at the KIC	8 (13%)
Other reasons	18 (30%)

Table 5: Usefulness of the KIC service

Useful dimension	Number (and percentage) of clients
The help that KIC staff gave to find information needed	52 (85%)
The internet access that KIC offers	19 (31%)
The email access that KIC offers	7 (12%)
Other aspects	6 (10%)
The multi-media resources that KIC offers	3 (5%)
The benefits advice sessions that KIC offers	3 (5%)

Table 6: Accessing information at the KIC

Statement	Number (and percentage) of clients			
	Agree	Disagree	Unsure/ No opinion	Not stated
I think the KIC should offer written materials (e.g. books) on more health topics	23 (38%)	8 (13%)	26 (43%)	3 (6%)
I found it easy to use the KIC to get the information I wanted on my own	23 (38%)	15 (25%)	16 (26%)	7 (11%)
I think that the KIC should be used EITHER by hospital staff OR patients/ visitors	19 (31%)	30 (49%)	8 (12%)	5 (8%)

I am happy with the DAYS on which the KIC is open	35 (57%)	4 (7%)	17 (28%)	5 (8%)
I think the KIC should extend its opening hours	23 (38%)	5 (8%)	28 (46%)	5 (8%)
I felt welcomed and valued at the KIC	57 (94%)	0 (0%)	0 (0%)	4 (7%)

Table 7: The KIC space and environment

Statement	Number (and percentage) of clients			
	Agree	Disagree	Unsure/ No opinion	Not stated
I think the layout of the KIC space makes it feel too cramped	11 (18%)	40 (66%)	8 (13%)	2 (3%)
I enjoy coming to the KIC	52 (85%)	0 (0%)	5 (8%)	4 (7%)
I think it is too noisy at the KIC	1 (2%)	50 (82%)	7 (11%)	8 (5%)
I think that the atmosphere at the KIC is warm and inviting	52 (85%)	1 (2%)	4 (7%)	3 (6%)

Table 8: Views on the KIC staff

Statement	Number (and percentage) of clients			
	Agree	Disagree	Unsure/ No opinion	Not stated
I understand the difference between health information and health advice	55 (91%)	2 (3%)	2 (3%)	2 (3%)
I found the form I had to complete to get help from the KIC too complicated	4 (7%)	31 (51%)	20 (33%)	6 (10%)
I found it easy to ask the KIC staff for help	58 (95%)	0 (0%)	0 (0%)	3 (5%)
I felt my privacy was respected when I asked KIC staff to help me	54 (88%)	1 (2%)	3 (5%)	2 (3%)
I thought that the KIC staff took too long to help me find the information I wanted	0 (0%)	56 (92%)	3 (5%)	2 (3%)
The depth and detail of the information given to me by KIC staff	52 (86%)	2 (3%)	5 (8%)	2 (3%)

met my needs				
I think that the format in which the information was given to me by KIC staff could have been better	5 (8%)	49 (81%)	5 (8%)	2 (3%)

Table 9: The impact the KIC has had

How KIC information helped me or someone else	Number (and percentage) of clients
Become more aware of a health issue	27 (75%)
Be more confident for a GP/ hospital visit	18 (50%)
Take action to prevent a health issue (e.g. heart problem)	10 (28%)
Manage a health condition (e.g. diabetes)	15 (42%)
Make a decision on which treatment to choose	11 (31%)
To learn more about medications that are being taken (e.g. side-effects)	10 (28%)
To gain confidence to search for more information around health issues	23 (64%)
To feel less isolated and lonely	13 (36%)
To get in touch with a support group	6 (17%)

Appendix Six: A copy of the KIC complex enquiry form

KIC enquiry form

Welcome to the KIC. To help us answer your enquiry, please complete this form.

Please explain your topic here clearly.

Please include any relevant details such as your age and any particular aspect of the condition or intervention.

What sort of information would you like? (please tick as many as apply)

- Condition overview Leaflet Book Research articles
Literature search Website Support Group Tape/video
Translation Other (please specify)

How would you like to receive this information?

- Post Email Telephone I will collect it on.....

Please write your contact details below:

Name:

Address:

Postcode:

Telephone No.

Email address:

Disclaimer: While we take every care to provide accurate and up to date information, we cannot guarantee its completeness and correctness. Advice given by the KIC should not be used to make a diagnosis, or as a base for any decisions about health or treatments. **The information given does not constitute medical or other professional advice, and should not be used without further consultation with a doctor or other appropriately qualified professional.** The provider of this information accepts no liability for loss or damage caused as a result of doing or refraining from doing any act as a result,

in whole or part, of any reliance on the information.

I have read the disclaimer, and agree with its statements.

Signed: _____ **Date:** _____

May we contact you in the future?

Would you be happy for us to send you questionnaires or surveys, which will help us improve our service?

Yes No

Would you like to be invited to Knowledge & Information Centre events such as public meetings or focus groups?

Yes No

Enquirer details:				
1. Member of the public				
NHS Inpatient	NHS Outpatient	Carer/relative/visitor	Other	
2. NHS Staff				
GSTT staff	SLAM staff	Lambeth PCT	Lewisham PCT	Southwark PCT
Other (which Trust) _____				
What type of job do they do?				
Doctor	Doctor in training		Nurse/Midwife	Scientist/Technician
Allied health professional			Manager	Admin & Clerical
Clinical support worker		Researcher	IT staff	Facilities
Other (please specify)				
3. Student				
KCL nurse	KCL medic	Other (please specify)		

How did they hear about the KIC?				
Leaflet	Postcard	Newsletter	Passing by	Intranet
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
KIC website	GSTT website	Induction	Event	Colleague/friend
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other				
<input type="checkbox"/>				

