

# Final Report November 2007

## Evaluation of the Cancer and Palliative Care Information Service (CAPCIS)

Prepared for  
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# Executive Summary

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## Background

FMR Research Ltd was commissioned in spring 2007 to evaluate the Cancer and Palliative Care Information Service (CAPCIS) website. CAPCIS, an internet information portal, or gateway, went live in September 2006, following over a year in development. It aims to provide information to patients, carers and professionals on cancer and progressive, life-limiting conditions. The site is now averaging over 100 visits per day but it is not possible to calculate the number of individual users or repeat visits or to profile users.

The aim of the evaluation was to examine whether the project's objectives had been met, to gauge the level of awareness of CAPCIS within its target audience and to make recommendations for the future development of the initiative.

## Method

The evaluation approach consisted of some desk research of website statistics and project reports, 15 depth interviews with staff and other key stakeholders, an online survey and paper based survey for patients and carers and nine focus groups with patients and carers throughout the Argyll & Clyde area. The response to the online and paper based survey was poor (26 and 7 responses respectively), so a larger number of focus groups were convened in order to gain a greater degree of feedback and involve more users/potential users in the evaluation.

## Results and discussion

### Awareness of CAPCIS

Whilst the CAPCIS team put a lot of time into marketing activity, this did not translate into high awareness of CAPCIS amongst stakeholders, patients and carers. The online survey was advertised on the CAPCIS website via a box and banner encouraging people to participate, but response remained low despite the survey being posted for nearly two months and focus group participants being encouraged to complete the survey and tell others to participate. Over 1,500 paper questionnaires were distributed to a range of different public points which had received CAPCIS information, but the response was less than 0.5%. Participants of the focus groups had a low awareness of the site.

The most common method of finding out about CAPCIS was word of mouth. Only two people had seen a CAPCIS leaflet.

### Use of CAPCIS

Use of CAPCIS was generally low amongst those involved in the evaluation, for example less than 10% of focus group participants used it. Amongst users, access to CAPCIS tended to come via the internet rather than information being printed out by health professionals. Survey respondents were more likely to be seeking information on support groups/voluntary organisations, or signposting to other services. Specific information about illnesses or symptoms and how to deal with various aspects of these were also sought. Two-thirds of survey respondents stated that they found what they were looking for on CAPCIS.

Over half (56%) of survey respondents accessed CAPCIS at work and 41% at home. Half of respondents (48%) had accessed CAPCIS between two and five times. Respondents were fairly evenly divided between those looking for information for other people and those seeking information for themselves. Those who were looking on behalf of another person were doing this because the other person could not access

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the site themselves (as they did not have internet access, were too ill or had a disability). Of these, two-thirds were seeking information for a client or patient rather than on behalf of a friend or relative.

Information on both cancer and progressive, life-limiting illnesses was sought by respondents.

### **Rating of CAPCIS**

Survey respondents were positive about the specific features, e.g. finding the right information, and accessibility of CAPCIS. Several participants rated it positively but others felt that they would have found the same information elsewhere, such as Google or another major site.

CAPCIS' blog and forum have not been well used. Few participants reported using this medium and, where they do, it tends to be when they need specific support on something rather than on a regular basis.

### **Strengths**

The CAPCIS website was perceived to be visually appealing, with a softer look than other NHS sites, and easy to navigate. The range of cancers and condition on which information was provided was perceived to be positive, but participants would like to see this expanded further. Focus group participants liked the lack of adverts on the CAPCIS site and the NHS brand was perceived to give users confidence in the accuracy of the information provided.

There were mixed views on the pros and cons of addressing both cancer and palliative care needs in one site, given people's lack of understanding around what the latter includes. On balance, the information was perceived to fit well together but work needs to be done on communicating to people what is included under palliative care. Promotion of less well known conditions was seen to be a strength.

### **Weaknesses**

A key weakness was perceived to be low awareness of the resource and low use of the site. CAPCIS was perceived to focus on cancer information. Many focus group participants felt they would not go further than the homepage if they were looking for information on progressive, life-limiting conditions. It was suggested that this may well have impacted on the uptake of leaflets, as people with progressive life-limiting conditions may not realise that the site is relevant to them too.

The name and perceptions of poor marketing and awareness raising were both seen to be weaknesses and areas for substantial improvement.

The information on the website was perceived to be too text heavy by some participants, albeit easy to navigate. Some pages require scrolling down which stakeholders feared might result in people missing information. The poor use of blog and forum was rated poorly and the young person's section wasn't seen to be as young person friendly as it could be.

The value for money of the CAPCIS project was queried given high resource levels and low usage rates.

### **Preferred information sources**

The majority of focus group participants prefer to receive information via word of mouth or leaflets from the GP/hospital. Where people used the internet to find information related to health, most reported using this as an additional rather than main or preferred source of information. The internet was seen to be available 24/7 but the perceived lack of an opportunity for active two way dialogue (with participants keen to see a telephone helpline) was seen to be a weakness. Fast, efficient and reliable internet connectivity is still an issue in some of the rural areas of Argyll & Clyde.

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Participants were clear that different individuals may wish very different levels of information and that they seek different sorts of information as they/the person they care for progresses through their illness. Focus group participants were particularly keen to find practical information as early as possible, as communication on benefits, aids & adaptations, etc., often comes too late and in a haphazard fashion.

## **Conclusions and recommendations**

The CAPCIS team have got a website up and running and it has been viewed relatively positively by those who have seen it. The creation of the website has been the main output of the project at this stage as awareness and usage is low (although growing month to month). Marketing and promotional activity has not been as effective as it could be and branding of the site is a clear issue. The general lack of internet usage is also an issue amongst the target groups. Participants required different information depending on their personal circumstances and their progress through their condition, for example, information on benefits, aids and adaptations often come too late.

Given that a substantial amount of money has already been invested in developing the CAPCIS resource, it would be unfortunate if this was now lost given that a little extra resource to ensure people know of it may result in higher usage rates and therefore positive outcomes for target groups. It is noted that it has been agreed that West of Scotland Cancer Network and Glasgow Palliative Care Network will take over CAPCIS once BLF funding ceases.

The research conducted for the evaluation would suggest the following specific recommendations for consideration:

- marketing activity should be reviewed and more effective means of raising awareness of CAPCIS amongst the target populations, e.g. particularly 'selling' it to consultants/GPs/other health care professionals as a means to add value to their role, as people listen to them;
- consideration should be given to changing the name 'CAPCIS' and the use of terms such as palliative care in order to be more accessible, clearer and to move away from the association of the term palliative with cancer only (this may also impact positively on it coming higher when people are searching for information via search engines);
- consumer testing could be more in-depth with target groups, e.g. young people, people from BME communities, people with different disabilities, etc., given some of the comments made;
- any work done to improve the accessibility of the site should be clearly notified on the information page so that those who might benefit from this, their carers and professionals know about this;
- local practical information could be provided, e.g. identifying which pharmacies pick up prescriptions, linking up volunteer drivers and those who need them, how to access aids & adaptations, who to go to for benefits advice and key questions to ask, etc., in addition to more information for carers;
- a telephone helpline would be welcomed by patients and carers as an alternative means of receiving information;
- if the blog is to be continued, members of the working group should initiate discussion on the blog to encourage others to participate;
- whilst the range of cancers/conditions was viewed positively, patients and carers would like to see this expanded; and
- consideration should be given to ways in which to gather more accurate data on website usage, to identify actual numbers and profile of users, gain insight into usage patterns and inform future development.

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# 1 Introduction

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## 1.1 Background

### 1.1.1 Context

Cancer remains the biggest cause of death in Scotland along with heart disease and stroke, however the picture is improving. In 2006, 7,692 males and 7,333 females died from cancer in Scotland. Taking all cancers combined, age-standardised mortality rates have fallen over the last 10 years (1996-2006) by approximately 8% (Cancer Mortality 2006, ISD Scotland data, <http://www.isdscotland.org/isd/5047.html>, accessed 1 October 2007). While survival rates are also improving, there are three times as many people living with cancer in Britain than there were 30 years ago (MacMillan, [http://www.macmillan.org.uk/About\\_Us/Why\\_we\\_exist/Why\\_we\\_exist.aspx](http://www.macmillan.org.uk/About_Us/Why_we_exist/Why_we_exist.aspx), accessed 1 October 2007), and the need for the provision of care, support, palliative therapy and quality information is growing.

Health was a priority topic for the New Opportunities Fund (NOF, now Big Lottery) in 2003, when the concept which became CAPCIS (Cancer and Palliative Care Information Service) was first mooted by the Health Council in Argyll & Clyde. Reliable patient information was perceived to be difficult to source, particularly information which was relevant to those living in Argyll & Clyde. The Argyll & Clyde area has urban centres in the south but has a large rural area to the north. This in part drove the concept of an internet resource, in addition to people having access to information 24/7, but also impacted on the way in which the CAPCIS team could liaise with professionals in the different parts of the health board area.

Cancer and chest, heart and stroke were all priority health areas but chest, heart and stroke was perceived to have sufficient resources at the time. Two bids were therefore developed, one focussed on cancer and one on palliative care. The bids had the support of medical directors within the NHS and, as they were led by the local Health Council they were perceived to be strongly grounded with patients and carers. The bids were approved by NOF, with funding of £207k for cancer care and £96k for palliative care over three years. The award of funding coincided with changes within the Health Council structure and so the projects were adopted by NHS Argyll & Clyde. Given that both were electronic information resources, it was agreed that they would be addressed within one site, which became [www.capcis.org.uk](http://www.capcis.org.uk).

### 1.1.2 What is CAPCIS?

CAPCIS is an internet information portal, or gateway, launched on 27 September 2006, which aims to provide an organised and up-to-date directory of key services, service providers and information on cancer and progressive, life-limiting conditions. The website has therefore only been 'live' for a year.

CAPCIS was designed to provide support to patients, their families, carers and healthcare professionals around cancer or other conditions where palliative care services are required. It is also available to the wider public as an information resource via the internet.

CAPCIS' main target group is those living, working and caring in Argyll & Clyde, which reflects the fact that it was established before the dissolution of NHS Argyll & Clyde at the end of March 2006.

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For patients, carers and the wider public, CAPCIS aims to provide:

- access to sources of reliable information about cancer, cancer prevention, screening, the availability of local services and other aspects of cancer care;
- access to sources of reliable information on progressive, life limiting conditions where palliative care is required, including the availability of local services; and
- signposting about services available in local hospitals, hospices, nursing homes, social work departments and other palliative-care services.

For healthcare professionals, CAPCIS aims to provide:

- access to reliable health information;
- convenient access to the best research evidence, clinical guidelines and decision support tools;
- support for clinical governance and quality of care initiatives; and
- effective means of communication with colleagues.

For health authorities, policymakers, managers and others responsible for the health of the whole population, CAPCIS aims to provide:

- support for local Health Improvement Programmes;
- efficient, secure data capture for research;
- work in partnership with links to and potentially merging with other wider initiatives, e.g. NHS24, Scottish Executive National Patient Information Initiative, WoSCAP and other IT based information initiatives; and
- PFPI.

There are three layers to the CAPCIS project:

- the project steering group;
- the project working group; and
- the project team.

The steering group comprises of up to twenty members, and has the role of advising on the design and implementation of the project, considering monitoring data and facilitating partnership working between the various organisations and institutions that contribute to the project.

It should be noted that NHS Argyll & Clyde was dissolved in March 2006, with NHS Greater Glasgow & Clyde taking over responsibility for the southern part of the area and NHS Highland for the northern part of the area from April 2006 onwards. This substantive change of administration had an impact on the membership of the steering group, in particular, because of staff turnover. Ten members of the current steering group (approximately half) were not original members of the steering group. Staff changes also had an impact on the team's networking with professional staff in Argyll & Clyde as some people moved post following dissolution.

The working group consists of up to twenty-five members and is concerned with assisting the Project team with content of the CAPCIS resource and ensuring the site is comprehensive, inclusive, community based, holistic, and up to date.

The Project team comprises of four people: the Project Manager (who is also co-chair of the working group), two Project Information Facilitators (PIF) and an administrator. The administrator role was added via a variation BLF bid, following the needs assessment and was in post from June 2007. There has also been turnover with one of the PIF posts since the project commenced. The Project team are concerned with the day to day operation of the CAPCIS gateway including liaison with the working group, and the technical aspects of maintaining and updating the site.

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The project provided a project plan, business case and needs assessment information to inform the evaluation. The project plan outlines how the project will be structured and informed, the timescales for the project and risks associated with it. Unfortunately, the risk of low awareness/lack of usage was not raised through this process. The original timescales for the project was 3 years and six months. This was reduced to 2 years and four months.

Prior to establishing the website, the CAPCIS team conducted a needs assessment with cancer patients, those with palliative care needs and health care professionals. A total of 1,500 questionnaires were issued to cancer patients via McMillan nurses and 46 were returned completed, a 3% response rate. 1,500 questionnaires were issued to those with palliative care needs and 50 completed responses were received, a response rate of 3%. CAPCIS staff reported that they also undertook qualitative discussions with patients/carers. The team visited 150 health care professionals, conducting one to one interviews to also inform the needs assessment. Information was then gathered for the website content and the website was designed. Each page was then checked by the working group and some client groups before being published. The project undertook staff and user satisfaction surveys pre and post launch of the site with support groups, out patient units, etc. The reports of these surveys were not available for inclusion in the evaluation, unfortunately. The project process had a final stage of amending information in light of this feedback. The Project Brief outlines the four stage followed: identifying needs; developing and piloting content and presentation, with user involvement; disseminate and use; and review.

### **1.1.3 Access**

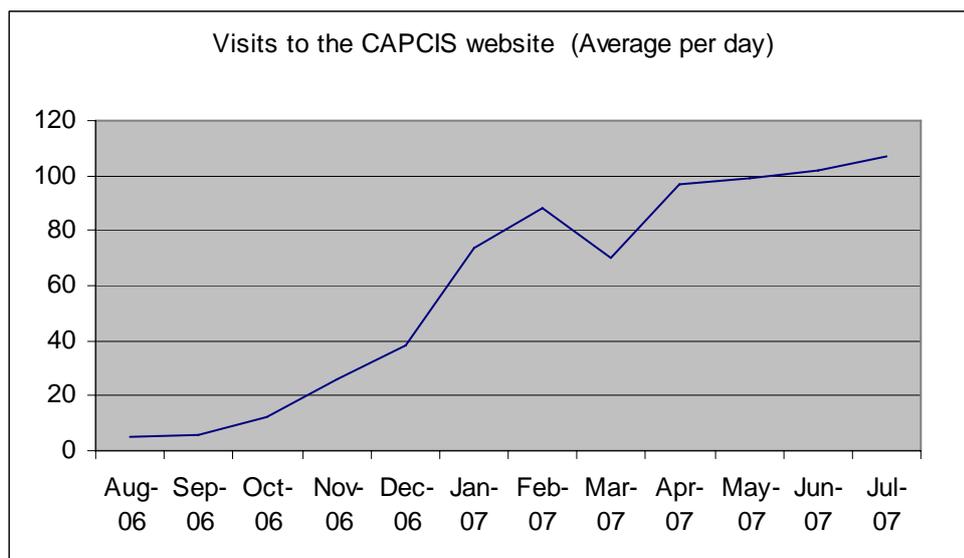
In terms of accessibility, the site has access keys, users can change the font size, the colour scheme has been selected to have greater levels of accessibility, there is an access statement, it is W3C accessible (W3C are international guidelines for web content developers to ensure websites are as accessible as possible to people with disabilities); it has been browser tested (different computers have different browsers, so websites need to be tested on different browsers to make sure they work properly on each) and beta tested (tested by a range of users to identify any bugs or flaws in the system). No information has been requested in alternative formats or languages and the proposed CD version of the website had also not been produced at the time of the evaluation. The project links to Deaf Cancer Wise and Fair for All.

15,000 information leaflets were distributed to a variety of locations (e.g. GP surgeries, health centres, oncology departments, carers' centres, pharmacies and libraries) within the former NHS Argyll & Clyde prior to the website being launched by the project team. The service has also been advertised through patient and carer support groups, general practitioners, local newspaper articles, radio advertisements (recently on Oban FM and Clyde 2) and word of mouth via members of the project team and working group. It is noted that NHSGGC Communications Team did not support the marketing and communications activity around the website as they do not support websites which are separate to the core NHSGGC website.

### **1.1.4 Usage figures**

The average number of visits to the CAPCIS website per day is shown in the figure below. This started with a very low 6 per day at the time of the launch in September 2006 and has grown to 107 per day in July 2007. There was a dip in March 2007 to 70 per day on average, dropping from 88 in February but increasing again to 97 in April, as can be seen in the figure below. It is noted that the evaluation was conducted relatively early in the life of CAPCIS and it would be expected that usage would grow over this time and beyond.

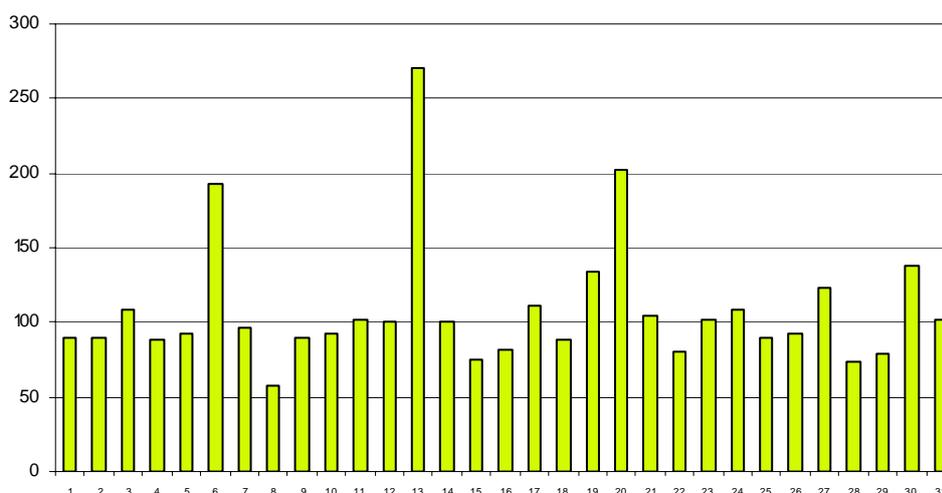
**Figure 1 Average daily visits to the CAPCIS website (August 2006 – July 2007)**



The CAPCIS website uses the Webalizer package to collect statistics on use of the website. Visits are the most useful statistic to look at in terms of website statistics. These are recorded when another server makes a request for a page on the website's server for the first time. There will usually be a default period, e.g. 30 minutes, after which any further requests will count as a separate visit. There is no way of knowing the number of repeat visitors, on separate occasions or those who 'time out', and therefore the actual number of people accessing the website from the Webalizer data. The number of hits, i.e. the total number of requests made to the server, are recorded but can be grossly skewed by search engine activity (as one visit by a search engine can generate thousands of hits as it searches each page on the site). Kbytes are also recorded and these simply refer to the amount of data downloaded when accessing the web.

The daily usage rates for July 2007, in the figure below, show higher numbers of visits on Fridays than any other day of the week.

**Figure 2 Daily visits to the CAPCIS website (1 – 31 July 2007)**



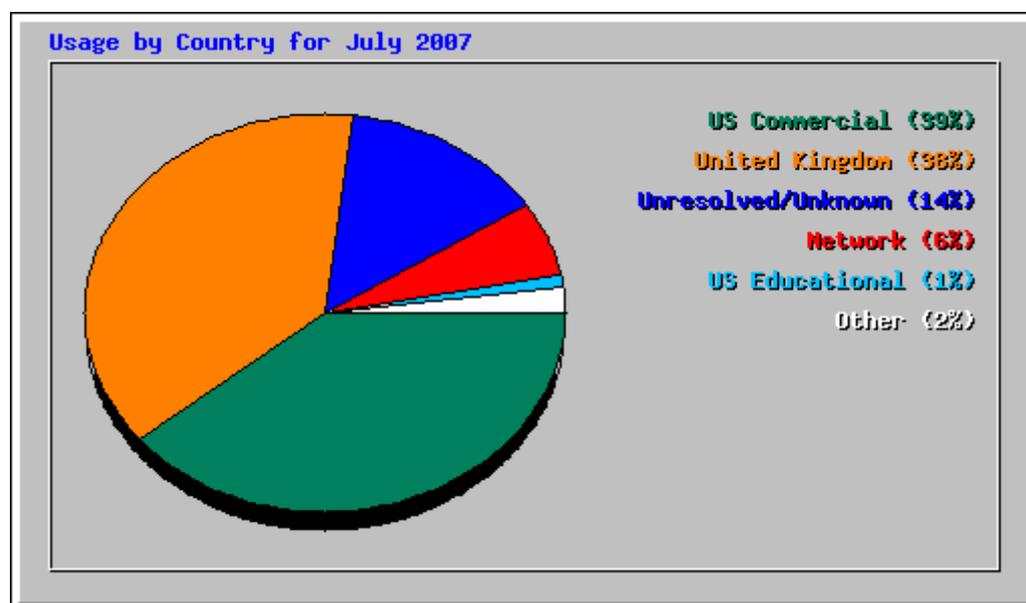
On average (in the period November 2006 to September 2007), 35% of hits (**not** visits) to the site were direct referrers. This was highest in January 2007 (46%) and May 2007 (46%) and lowest in August and September 2007 (both 24%). Referrers are those URLs that lead a user to the website or cause the browser to request

something from the server. The vast majority of requests are expected to be from the site's own URLs as most website pages contain links to other objects such as graphics files. So, for example, if a page has 10 graphic images, then each request for the page will produce 10 more hits with the referrer being the website's own page. This does not therefore mean that 35% of people accessing the website directly typed in [www.capcis.org.uk](http://www.capcis.org.uk), but that a lower proportion did (albeit that we cannot calculate how many specifically as this is measured in hits rather than visits).

Search string data can provide some information on what people are searching for via search engines but is only available if that information is contained in server logs and this data may not be captured for all search engines. The number of search string hits highlighted in the web statistics appears to be quite low in number each month, but the most common search criteria appears to be 'capcis' or a variation on this (for example, some people have searched on the website name or part of it). Other search strings reflect some very specific queries users have in terms of cancer or palliative care conditions and association information. There are some generic search strings, e.g. geographic areas or people's names, but most are relevant to the main purpose of the CAPCIS site.

Unfortunately, the Webalizer package does not record very useful information in terms of where users are based geographically. The figure below shows most users of the site to have a .com domain (called US commercial users on Webalizer) (39%). The UK are the next highest users at 38% and there are 14% unknown users. Very little can be usefully interpreted from this data as many users in the UK have .com domains and there is no way of knowing in which part of the UK they reside. It is therefore impossible to tell how many users live or work in Argyll and Clyde from this data. It is noted from the hourly usage rates for each month that the majority of activity is during the day in the UK, although there is still a reasonable degree of activity overnight, which would suggest that the majority of users are based in the UK.

**Figure 3 Usage of the CAPCIS website by country (July 2007)**



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## 1.2 Objectives

CAPCIS wished to commission an independent evaluation to examine whether the project's objectives have been met, to gauge the level of awareness of CAPCIS within its target audience, and to make recommendations for the future development of the initiative.

The research questions are stated in the brief as follows:

1. Is CAPCIS a one-stop-shop, i.e. does it fully meet the information needs or direct users to sites that meet the information needs of:
  - people with cancer;
  - people with other progressive life limiting conditions;
  - informal carers;
  - health professionals; and/or
  - young people.
2. If the information needs of the groups listed above have not been met, what information is missing? Is the internet the best way of presenting the information required? Do the user groups have comments on the usability of the website?
3. From samples of fifty individuals diagnosed with cancer, fifty individuals diagnosed with a progressive life limiting condition and fifty informal carers (i.e. 150 people in total), determine:
  - awareness of CAPCIS;
  - how they heard about CAPCIS, if at all;
  - how CAPCIS could be best publicised;
  - how many have used CAPCIS, and in what ways;
  - did CAPCIS meet people's information needs; and
  - any barriers to accessing CAPCIS.
4. What are the key learning points for others who may wish to develop a similar project?

CAPCIS is currently discussing possibilities for future expansion with organisations such as the West of Scotland Cancer Network and West of Scotland Palliative Care Network. CAPCIS's current funding extends until November 2007. It is intended that this evaluation will demonstrate the extent to which CAPCIS has been effective, as well as providing recommendations for its future development, direction and possible expansion.

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## 2 Method

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The methodology was as follows.

### 2.1 Overview

The study consisted of a number of elements, as follows:

- desk research;
- research tool development;
- depth interviews with staff and other stakeholders;
- survey of service users (online and postal);
- focus groups with patients/carers; and
- analysis and reporting.

Each of these are explored in more detail below.

### 2.2 Desk research

Brief desk research was conducted to review key documents, literature and statistics connected to CAPCIS. This included the original CAPCIS funding application, website statistics (e.g. hits, unique hits, user behaviour, etc.), needs assessment information, the business case and the project plan.

### 2.3 Research tool development

Several different research tools were designed, with commonality between these but differentiation depending on the means of administration and whether they were qualitative or quantitative in nature.

The following research tools were designed:

- online survey questionnaire;
- broadcast survey questionnaire;
- focus group topic guide (patients/carers);
- telephone interview questionnaire for patients/carers (with mostly closed questions);
- topic guide for depth interviews with health professionals; and
- topic guide for depth interviews with CAPCIS personnel.

All research tools were drafted for comment by the research steering group, prior to being finalised.

### 2.4 Surveys of service users

The commissioning team were clear that both an online and paper based broadcast survey be undertaken, despite the research team's concerns over potential low response rates.

#### 2.4.1 Online survey

The CAPCIS website displayed a link which visitors could click upon to participate in the online survey, hosted on our online survey site (opinion-online.com). All data was therefore routed directly to us and stored on our secure server.

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The success of an online survey depends very much on the volume of visitors to a website, and the relevant visitors (i.e. patients/carers, health professionals, etc.) being able and prepared to take the time to complete a questionnaire. CAPCIS has relatively low visitor numbers (and many of these are from outwith Argyll & Clyde) and response to the survey was also low – 26 people gave an online response over a period of nearly two months. This response was raised, to some degree, by focus group participants also giving their views online.

It had been proposed that the online and broadcast surveys would serve as a recruitment vehicle for participation in focus groups or telephone depth interviews. However, this was not possible given the low response rates.

#### **2.4.2 Broadcast survey**

Fifteen thousand promotional leaflets were sent out to various locations within the former NHS Argyll & Clyde area prior to the website going live and the commissioning team were keen that a broadcast survey (paper-based, self-completion) was also distributed widely throughout the Argyll & Clyde area. FMR made it clear at the commissioning meeting and in the proposal that this was not likely to result in a high response rate and this proved to be the case – just 7 responses were received from over 1,500 questionnaires distributed to 100 sites by FMR (a 0.5% response rate) and it is our understanding that CAPCIS personnel also distributed questionnaires to a number of pharmacies. All sites were contacted by telephone in the first instance to ensure that they were received by an individual who had committed to displaying/circulating these in an appropriate way.

### **2.5 Qualitative research with patients/carers**

It had originally been intended that both focus groups and telephone depth interviews would be conducted with patients and carers. The survey and contact with a variety of different support groups/organisations did not yield participants for telephone interviews so it was agreed that nine focus groups would be conducted, throughout the Argyll & Clyde area. Groups were conducted in Paisley, Greenock, Lochgilphead, Oban, Dunoon, Helensburgh, Glasgow and Tighnabruaich. A focus group with a young persons' cancer support group was also conducted in Glasgow.

Group participants were recruited from a variety of support groups and voluntary organisations on the CAPCIS contact database, to ensure a good spread of patients and carers participated in the study and that different illnesses or conditions were reflected. Whilst the number of participants was explained when liaising with groups, it was difficult to know how many people might be attending each group, particularly where participants were drawn from more than one source. Group size varied from 1 (in Dunoon) to 12 in Oban. A total of 63 participants gave their views via focus group, with an average of 7 people per group. The youngest participant was 17 and the oldest estimated to be in their seventies. There was representation of each age group in between (people in their 20s, 30s, 40s, 50s and 60s), but there were more participants aged 40 plus than under 40. There was good representation from both men and women.

### **2.6 Depth interviews with stakeholders**

We conducted 15 depth interviews with the CAPCIS team, steering group, working group and other stakeholders. All CAPCIS team members were interviewed and chairs of both steering and working groups were interviewed. Other members of the steering and working group were selected at random as there were more group members than interviews required.

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## **2.7 Analysis & reporting**

Once data collection was complete, analysis of both qualitative and quantitative data was gathered. This report outlines the findings from the study.

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## 3 Results and discussion – surveys

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### 3.1 Introduction

Two surveys were undertaken – one was online, which visitors to the website could complete and one was paper-based and issued to a wide range of different venues. As stated in the method section, the response to both surveys was very low: twenty-six people participated in the online survey and seven returned completed paper questionnaires. We are aware that some online respondents are likely to be participants in the focus groups, as the website and the associated survey was highlighted during the focus groups, with some responses made the day after a focus group.

Given the low response, the following data is provided for information and can really only be seen to represent the views of those who responded rather than be seen as a definitive view of users or potential users of the CAPCIS website.

### 3.2 Profile of respondents

Twenty-one respondents lived in the Argyll & Clyde area and twelve did not. Seven respondents were from Glasgow, six from Paisley, two from Dunoon, two from Barrhead and two from Bishopbriggs. Other areas were represented by one individual only.

Three-quarters of respondents (76%, 25 respondents) live in an urban area and 24% (8 respondents) in a rural area.

No respondents were aged 16 – 24 and only one person was aged 65 or over. There was an even split between those aged 25 – 44 (48%, 16 respondents) and those aged 45 – 64 (48%, 16 respondents). The majority of paper based questionnaires were completed by those aged 45 plus (6 of 7) and slightly more people who responded online were 25 – 44 (58%, 15 respondents) than 45 – 64 (42%, 11 respondents).

The majority of respondents were female (79%, 26 respondents) and 21% (7 respondents) were male.

The majority of respondents had no disabilities (91%, 30 respondents). Two had a mobility problem and one stated they had a disability which was not listed.

All respondents were white. The majority (85%, 28 respondents) stated that they were heterosexual, two (6%) that they were gay or lesbian and three (9%) that they would prefer not to state their sexuality.

### 3.3 About CAPCIS

#### 3.3.1 Awareness of CAPCIS

Respondents had become aware of CAPCIS from a number of different routes. A quarter (24%, 8 respondents) had first found out about it from a friend, colleague or family member. One in eight (12%, 4 respondents) had first found out from a patient/carer support group and the same proportion had found out via hospital. The full range of responses is shown in the table below.

**Table 1 How did you first find out about CAPCIS?**

	Total	
	No.	%
Friend, colleague or family member	8	24%
Patient/carer support group	4	12%
Hospital	4	12%
CAPCIS team member	3	9%
Leaflet or poster	3	9%
GP	3	9%
McMillan nurse	2	6%
WOSCAN	2	6%
Internet search engine (e.g. Google)	1	3%
Other	3	9%
Total	33	100%

Nearly one-third of respondents had heard of the CAPCIS website prior to its launch in September 2006, suggesting that these respondents were involved in its development in one way or another. A further 26% (8 respondents) became aware of it in September/October 2006. There was also a cluster of respondents who were very recently aware of CAPCIS (2 in May and 4 in June 2007), which might suggest that at least some of these were prompted to visit the site after becoming aware of it via the evaluation research.

Nine respondents (30%) first used CAPCIS in June 2007. The table below shows the pattern of responses in terms of when respondents first heard of CAPCIS and when they first used it.

**Table 2 When did you a) first hear about, and b) first use CAPCIS?**

	First aware of		First used	
	Total		Total	
	No.	%	No.	%
Before September 2006	10	32%	3	10%
September 2006	4	13%	4	13%
October 2006	4	13%	3	10%
November 2006	1	3%	2	7%
December 2006	1	3%	0	0%
January 2007	1	3%	1	3%
February 2007	0	0%	3	10%
March 2007	3	10%	3	10%
April 2007	1	3%	2	7%
May 2007	2	6%	0	0%
June 2007	4	13%	9	30%
Total	31	100%	30	100%

### 3.3.2 Accessing CAPCIS information

The majority of those responding (88%, 29 respondents) stated that they have mainly accessed CAPCIS information via the internet. One person stated that a carer/support person had printed it for them and three stated that they had never accessed it before. The respondent who had received printed information found this to be very useful.

### 3.3.3 Types of information sought

A wide range of information had been sought by respondents, as can be seen from the table below. The most common two responses were information on support groups, self-help or voluntary organisations (58%, 19 respondents) and signposting to other services (52%, 17 respondents).

**Table 3 Please tell us the types of information you were looking for?**

	Total	
	No.	%
Support groups, self-help or voluntary organisations	19	58%
Signposting to other services	17	52%
Illnesses or symptoms	9	27%
Types of treatment available	8	24%
Palliative nursing care	8	24%
Complementary therapies (e.g. aromatherapy, relaxation, herbal medicine, Reiki, etc.)	8	24%
Bereavement support	7	21%
Advice on mobility issues	6	18%
Legal advice (e.g. making a will, sick pay, employment law)	6	18%
Financial information (e.g. money matters, benefits)	6	18%
Controlling and relieving pain (palliative therapy)	6	18%
Possible side-effects of different treatments	6	18%
Causes of illnesses	5	15%
Advice on talking to children about illness	4	12%
Healthy lifestyle choices	4	12%
Advice on family and relationships	3	9%
Information on body image or prosthetics	3	9%
Spiritual or religious support	3	9%
Not accessed website before	3	9%
Total	33	100%

For each of these different types of information, at least 67% of respondents looking for information stated that CAPCIS helped them find what they were looking for. The table below shows the responses for each type of information/support. The lowest incidences of CAPCIS helping respondents to find the information they required were advice on mobility issues (67%, 4 respondents); advice on family and relationships (67%, 2 respondents) and bereavement support (71%, 5 respondents).

**Table 4 Did CAPCIS help you find this information?**

		Total	
		No.	%
Signposting to other services	Yes	15	88%
	No	2	12%
Support groups, self help or voluntary organisations	Yes	15	79%
	No	4	21%
Bereavement support	Yes	5	71%
	No	2	29%
Advice on family and relationships	Yes	2	67%
	No	1	33%
Advice on talking to children about illness	Yes	3	75%
	No	1	25%
Advice on mobility issues	Yes	4	67%
	No	2	33%
Information on body image or prosthetics	Yes	3	100%
	No	0	0%
Legal advice (e.g. making a will, sick pay, employment law)	Yes	5	83%
	No	1	17%
Financial information (e.g. money matters, benefits)	Yes	5	83%
	No	1	17%
Causes of illness	Yes	4	80%
	No	1	20%
Illnesses and symptoms	Yes	8	89%
	No	1	11%
Types of treatment available	Yes	7	88%
	No	1	13%
Palliative nursing care	Yes	7	88%
	No	1	13%
Controlling and relieving pain (palliative therapy)	Yes	6	100%
	No	0	0%
Possible side-effects of different treatments	Yes	5	83%
	No	1	17%
Healthy lifestyle choices	Yes	4	100%
	No	0	0%
Complementary therapies (e.g. aromatherapy, relaxation, herbal medicine, Reiki, etc.)	Yes	8	100%
	No	0	0%
Spiritual or religious support	Yes	3	100%
	No	0	0%

### 3.3.4 Difficulties in accessing information

Only one respondent stated that they had experienced difficulties in accessing CAPCIS information, but did not give any information on the nature of those difficulties.

## 3.4 Using the internet and the CAPCIS website

All respondents stated that they use the internet.

### 3.4.1 Where people access the internet

The two places where the majority of respondents access the internet were at work (56%, 18 respondents) and at home (41%, 13 respondents). One respondent accesses the internet elsewhere for free, e.g. at a library. Women, those aged 25 –

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44, those in urban areas, those in Argyll & Clyde and completing the questionnaire online were all more likely to mainly access the internet at work.

### **3.4.2 Degree of comfort with using the internet**

Three-quarters of respondents (73%, 24 respondents) stated that they were very comfortable in using the internet and the remainder were quite comfortable (27%, 9 respondents). Those aged 25 – 44 were more likely to state they were very comfortable (88%, 14 respondents in comparison to 59%, 10 respondents of those aged 45+).

### **3.4.3 Number of visits to CAPCIS**

Nearly half of respondents (48%, 16 respondents) had looked at the CAPCIS website between two and five separate times. A further five (15%) had looked at the site six to ten times and one person more than ten times. Seven respondents (21%) had only visited the site once and four (12%) stated that they had never visited the site (three of whom completed the survey online – presumably this was their first visit, possibly as they had been asked to complete the survey).

Those who had visited the CAPCIS site were then asked a range of questions about the website.

### **3.4.4 Overall rating in finding information**

Respondents were first asked to rate the CAPCIS website in terms of helping them to find the information they were looking for. All respondents were positive: 54% (15 respondents) found it very useful and 46% (13 respondents) quite useful. Interestingly, those based outside Argyll & Clyde were more positive in their ratings (70%, 7 respondents, rated the site as very useful in comparison to 44%, 8 respondents, of those in A&C). Those who responded on a paper questionnaire were also more positive (80%, 4 respondents, rated the site as very useful compared to 48%, 11 respondents online).

### **3.4.5 Rating of specific aspects of the site**

A number of aspects of the site were then tested with respondents, to establish how easy or difficult they found them to use. Again, the majority of respondents were positive in their ratings, although the degree to which they rated different aspects as very or quite easy varied, as can be seen from the table below. Reading text and understanding information scored higher 'very easy' ratings (62%, 18 respondents, and 57%, 16 respondents respectively) than finding your way around the site and finding the right information (39%, 11 respondents, and 32%, 9 respondents respectively).

One respondent rated finding their way around the site as quite difficult and one respondent also rated finding the right information as quite difficult.

**Table 5 How easy or difficult to use was the website in terms of these different things?**

		Total	
		No.	%
Reading text	Very easy	18	62%
	Quite easy	11	38%
	Quite difficult	0	0%
	Very difficult	0	0%
	Total	29	100%
Understanding information	Very easy	16	57%
	Quite easy	12	43%
	Quite difficult	0	0%
	Very difficult	0	0%
	Total	28	100%
Finding way around site	Very easy	11	39%
	Quite easy	16	57%
	Quite difficult	1	4%
	Very difficult	0	0%
	Total	28	100%
Finding the right information	Very easy	9	32%
	Quite easy	18	64%
	Quite difficult	1	4%
	Very difficult	0	0%
	Total	28	100%

### 3.4.6 Internet fora

CAPCIS has blogs and fora for different interest groups but no-one has used these features of the website, so we asked a number of questions around use of internet fora and reasons for not posting a message to date on CAPCIS. Just four respondents (17%) stated that they had ever posted a message or comment on an internet forum. Of these, one respondent had only ever posted a message once or twice, two had posted messages more than twice but less than ten times and one had posted more than ten messages. All respondents who had posted messages online were female, aged 45 plus, lived in an urban area and completed the survey online.

The two most common reasons given for not posting a message or comment on an internet forum were that it is not of interest (28%, 5 respondents) and a lack of time (17%, 3 respondents). Three respondents did not wish to share their experiences in this way/with strangers and two did not feel confident enough to do it. One person did not find them to be useful and one was a professional so unwilling to post a message.

### 3.4.7 Local services and support

Just under half of respondents (48%, 14 respondents) had used the Local Services and Support section of the CAPCIS website and the balance had not. All male respondents had done so (in comparison to 35%, 8 respondents, of females), 57% of those aged 45 plus had done so, 61% of those in urban areas compared to none in rural areas and 64% (7 respondents) of those outside Argyll & Clyde in comparison to 39% (7 respondents) of those in Argyll & Clyde.

Of those who had used this part of the website, 57% (8 respondents) rated it as very good and 43% (6 respondents) as quite good.

### 3.4.8 Rating the 'look' of CAPCIS website

Four different aspects of the way the CAPCIS website looks were then tested: the text, e.g. size, font and layout; images; balance of text and images; and colours used. Again, all were rated positively by respondents, with 54-68% of respondents rating them as very good. Responses are shown in the table below.

**Table 6 How do you rate the look of the CAPCIS website in terms of the following aspects?**

		Total	
		No.	%
Text (e.g. size, font, layout)	Very good	18	62%
	Quite good	11	38%
	Quite poor	0	0%
	Very poor	0	0%
	Total	29	100%
Images	Very good	16	59%
	Quite good	11	41%
	Quite poor	0	0%
	Very poor	0	0%
	Total	27	100%
Balance of text and images	Very good	15	54%
	Quite good	13	46%
	Quite poor	0	0%
	Very poor	0	0%
	Total	28	100%
Colours used	Very good	19	68%
	Quite good	9	32%
	Quite poor	0	0%
	Very poor	0	0%
	Total	28	100%

### 3.4.9 Missing from the website

The final question in this section asked if there was anything missing from the website, such as links to particular websites, types of information, accessibility features, etc. Five respondents made suggestions, as follows:

- a button to enlarge text;
- information re. Parkinson's support groups in Paisley;
- links to external websites were good but when they were closed the link to CAPCIS was also lost (this is a condition of W3C accessibility guidelines, but may also impact on the number of visits if people close the window and then have to go back to capcis to continue using the site);
- the name is too long, not easily remembered; and
- only had a quick look, not in detail. Alzheimer Scotland has a lot of info – worth taking people directly to info link. Don't recall the helpline number being on homepage. Perhaps a link to the Scottish Executive for info on adults with incapacity.

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## **3.5 The person the information was for**

### **3.5.1 Who was the information for?**

Responses were split between those who were looking for information for someone else (57%, 17 respondents) and those who were looking for information for themselves (43%, 13 respondents). Whilst all men were looking for information for themselves, the majority of female respondents were looking for someone else (74%, 17 respondents). Those who live outside Argyll & Clyde (55%, 6 respondents) were slightly more likely to be looking for information for themselves, whilst the majority of those who live in Argyll & Clyde were looking for information on behalf of someone else (63%, 12 respondents).

Those who were seeking information on behalf of someone else were asked why they were looking for this information. Five respondents (29%) were looking because the individual did not like using the internet and a further 24% (4 respondents) because the individual did not have access to the internet. Three (18%) were looking as the person was too ill and 12% (2 respondents) because the person has a disability. Three respondents were seeking information for a patient and one for a person who had applied for help to a support group. One respondent had not used the site for a long time and so was just testing it for ease of use and to see what information was on it. One person did not give a response.

### **3.5.2 Relationship between person using the site and person seeking information**

Two-thirds of those looking for information for someone else were looking on behalf of a patient or client (69%, 11 respondents), 19% (3 respondents) were looking for a friend and 13% (2 respondents) were looking on behalf of another relative.

### **3.5.3 Profile of person seeking information**

All respondents were then asked whether the person seeking information from CAPCIS (regardless of whether this was for themselves or someone else) was worried about/being investigated for/currently has/has previously had cancer or a progressive, life-limiting condition. Half of those who responded to this question (only 24 people responded) stated that the person seeking the information currently has cancer (50%, 12 respondents). One-third are being investigated for cancer (33%, 8 respondents), 25% (6 respondents) have previously had cancer and 17% (4 respondents) were worried about cancer. Nearly half (46%, 11 respondents) currently have a progressive, life-limiting condition, 17% (4 respondents) were worried about a progressive, life-limiting condition and 4% (1 respondent) were being investigated for this. This was a multiple response question as professionals may have been responding on behalf of more than one patient/client.

**Table 7 Is this person worried about, being investigated for, do they have, or have they previously had cancer or a progressive, life-limiting condition?**

	Total	
	No.	%
Worried about - Cancer	4	17%
Being investigated for - Cancer	8	33%
Currently has - Cancer	12	50%
Has previously had - Cancer	6	25%
Worried about - Progressive, life-limiting condition	4	17%
Being investigated for - Progressive, life-limiting condition	1	4%
Currently has - Progressive, life-limiting condition	11	46%
Total	24	100%

### 3.5.4 Conditions on which information was sought

Respondents were asked which specific types of cancer or progressive, life-limiting condition information was sought on. The most common cancers cited were breast (53%, 10 respondents), bowel (42%, 8 respondents), lung (21%, 4 respondents) and prostate (21%, 4 respondents). The most common progressive, life-limiting conditions cited were dementia or Alzheimer's disease (36%, 4 respondents), Multiple Sclerosis (27%, 3 respondents) and kidney disease or failure (18%, 2 respondents). The tables below show the responses given in full.

**Table 8 Which condition/s did the information relate to? Cancer related information**

	Total	
	No.	%
Breast	10	53%
Bowel	8	42%
Lung	4	21%
Prostate	4	21%
Liver	2	11%
Head	1	5%
Skin	1	5%
Thyroid	1	5%
Total	19	100%

**Table 9 Which condition/s did the information relate to? Progressive, life-limiting condition related information**

	Total	
	No.	%
Dementia or Alzheimer's Disease	4	36%
Multiple Sclerosis	3	27%
Kidney (renal) disease or kidney failure	2	18%
Huntington's Disease	1	9%
Lung disease (e.g. emphysema, COPD)	1	9%
Motor Neurone Disease	1	9%
Parkinson's Disease	1	9%
Stroke	1	9%
Other	1	9%
Total	11	100%

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## 4 Results and discussion – focus groups

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### 4.1 Overview

Nine focus groups were convened with patients and carers, across the Argyll & Clyde area. Groups were held in Paisley, Greenock, Helensburgh, Glasgow (2 groups – one with younger people), Dunoon, Lochgilphead, Tighnabruaich and Oban. Over the course of all the groups, there was representation by those with cancer, those who were in remission and those who were caring for people with cancer. People with direct experience of Parkinson's, Multiple Sclerosis, Stroke, Motor Neuron Disease and Dementia and carers for people with these conditions also participated, with a mix of age groups represented. This provided a good spread of perspectives and opinions.

Images from the CAPCIS website were shown via laptop and projector and/or screen prints of the site where venues had no internet access in all except one venue (where it was clear that very few participants used the internet at all and they had looked at the site prior to attendance; and the group size plus small room prohibited projection).

### 4.2 Awareness of CAPCIS

It must be made clear at the outset that, whilst participants were recruited primarily from support groups with which CAPCIS has been in touch and who appear on the website, very few participants had heard of CAPCIS prior to being invited to take part in the group discussion. One support group reported only hearing from CAPCIS recently and only just having received leaflets. This can be seen to be a finding of the research in itself.

Beyond notification of the focus group, only four participants had heard of CAPCIS via direct contact from members of the team. One of these organised a support group and heard of CAPCIS at the launch, one had attended a support group meeting where a CAPCIS team member had visited (and they had then referred their daughter to the site) and another was the contact person for CAPCIS and had reviewed it for the support group's newsletter (which other group members claimed to have read but not referred to).

In addition, a few other participants had visited the CAPCIS site prior to attending a focus group, once they heard of it upon invitation, but this was still only a small proportion of total attendees as many participants did not have access to the internet (or, indeed, wish to do so).

### 4.3 Frequency of use of CAPCIS

Of the four participants who had heard of CAPCIS prior to being invited to participate in a focus group, one person and their daughter had looked at it soon after they found out about it and had used it "a few times" but not since; one who had found out about it at the launch had not felt the need to use it personally and had only referred others to use it prior to their participation in the focus group; and the other had refreshed their memory of the site prior to the focus group but not been a regular user or referrer other than via the newsletter. Participants were quick to comment on low awareness and usage rates, however.

All of these users had used the CAPCIS website online. If people have found an internet site which they consider to be useful, they will often save it as a 'favourite' or

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type the web address directly in. However, the majority of participants who use the internet said that they would be more likely to 'Google' for information relevant to what they were looking for.

Only one participant recalled ever being printed off information by a health professional/support group (their breast cancer nurse had printed off information from the Breast Cancer Care site).

Around half of all participants in the focus groups had access to the internet in some form (either themselves or a family member had access). Confidence in using the internet varied, as did regularity of use.

A couple of older participants stated that they get their children to look information up on the internet for them, but none stated that they would seek assistance from health professionals or elsewhere.

#### **4.4 Preferred information sources**

The majority of participants preferred to receive information via word of mouth (from their GP or consultant) or leaflets from the GP/hospital (as these were perceived to be more reliable than the internet). Where people used the internet, this was one source of information for them but was not always the preferred source, more of an additional one. For a few, it was the first port of call for information, albeit not something they would use daily, just when required. One of the key perceived drawbacks of the internet was that it did not provide an opportunity for two-way dialogue in the same way as talking to someone, and so does not address emotional support issues (and indeed may cause further distress), or answer specific personal queries.

It is recognised that the internet does have fora/chatrooms which could provide some support of this nature, but very few internet users had used these or were keen to do so: *"blog is a four letter word"*. One participant who had used an online forum found these to be useful in times of need, e.g. when they wanted to hear of other people's experiences regarding treatment, getting tips, etc. *"as they've been there and done it"*, but felt they were very negative and could be depressing so would not wish to use them on an ongoing basis. Another participant suggested that it would at least be useful if people could email a question and receive a response. One participant had attempted to use the forum prior to the focus groups but had experienced problems: *"it says to fill in the form at the bottom of the page – there isn't one!"* (Users have to click on terms and conditions before accessing the forum. The forum has 170 registered users but has currently been suspended.)

Only two people participating in one of the focus groups had seen a CAPCIS leaflet. They felt that it was very much aimed at cancer patients so people with other conditions would not think it was relevant for them. They suggested that CAPCIS needed promotional materials that captured people's attention and were clear on the types of people who might be helped by it, rather than just leaving people to assume that cancer and palliative care was not for them.

Whilst, people expressed a preference for leaflets, GP surgeries were perceived to have *"too many leaflets so you tend not to look at any"*. This would suggest that being given relevant leaflets by health professionals would be preferable rather than relying on patients/carers to pick something up themselves and have to filter what was/was not relevant to them. Participants also reported not attending their GP very often so they would not access leaflets there in any case. Public places such as libraries and supermarkets were suggested as more appropriate locations to reach a wider number of people.

Leaflets were also perceived to provide a brief introduction rather than a full explanation and several participants stated that they wanted more detail than leaflets tended to provide – *"I want to know the nitty gritty"*.

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Some charities produce magazines, which are also of use to patients and carers, for example the Parkinson's Society issues a quarterly magazine which was rated highly. Organisations such as Breast Cancer Care also provide literature in leaflet form, plus a 'buddy' to help people through their illness. Organisations like the Princess Royal Trust for Carers was also rated highly as a first stop for information and support (for both patients and carers).

No participants had heard the radio adverts for CAPCIS. Participants in Oban stated that those in some areas locally could not receive Oban FM (they only get Radio 2 sometimes) and participants in Lochgilphead were unaware that Oban FM existed at all! They felt that most people in that area listen to Argyll FM on Saturdays and Sundays so that would be a better place to advertise. Local newspapers were suggested as a more appropriate medium for communicating information to local people.

The type and amount of information varied by the timing of a participant's illness. For example, those who have experienced treatment more recently talked more readily of information they had been given but those who had been treated a few years ago said there was no information then apart from what their consultant/GP told them. Given that people were talking about the 1990s and even before this, there is a caveat on this information in terms of the degree of reliable recall which could be expected.

There were some concerns about the veracity of information found on the internet, in more than one discussion, even to the extent that doctors had advised one person against looking on the internet for information:

*"You can clutch at straws on the internet."*

*"Some US sites offer 'cures' – you need to be careful."*

*"The doctor told me not to look at the internet."*

#### **4.5 Type of information sought**

One participant described the internet as *"a big library"* so they could select as much or as little information as they wished. There was some discussion in more than one group about the amount of information different people might wish to have. This was seen to be a very personal choice – some people *"prefer to stick their head in the sand"* and others wish to have as much information as possible and become lay experts on their condition/the condition of the person they care for. There was also a view that consultants/health professionals often did not wish to give too much information at any one time, but *"drip feed"* information as patients reach different stages.

People who had used the internet to find information on their condition/that of those they cared for felt that the need for information, and type of information varied by the stage they were at. For example, they sought information on the condition and its implications pre and immediately post diagnosis (although others felt patients were not ready for information at diagnosis but would have lots of questions at the second appointment, once they were in treatment), sometimes looking for information on support groups (but this varied by individual), then often did not look again until they had increased care needs and were looking for advice on this. Those who were in remission or who had already *"done my homework"* on their condition did not feel that they needed to refer to an information resource such as CAPCIS. One exception to this was access to and cost of travel insurance after being in remission from cancer for five years.

Participants felt that they get medical information which is tailored to them from the clinicians, but practical information such as how to get a home help, or benefits would be particularly helpful. If you are feeling unwell, it is difficult to motivate yourself and physically pursue things given that *"sometimes you have to know the right questions*

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to ask to get the information you need". Participants at some of the focus groups learnt useful tips from other participants in this regard.

The internet was also perceived to be useful for family and friends who may not receive information directly from clinicians *"we always get half the story, second hand"* and who may wish to know things they would have difficulty asking their loved one, for example whether Parkinson's Disease is hereditary or not.

Carers were clear that it was assumed by health professionals that they did not need any help, but that was not the case. Information about respite care, home helps, McMillan nurses, benefits, aids & adaptations were all things that carers felt had come to them too late and in a disjointed rather than co-ordinated way, and some had still not resolved some of these support needs. Information on what kind of support available to carers and where/how to get it was seen to be invaluable.

One participant who had looked at CAPCIS prior to attending the focus group felt that there was a lot of information for patients but not for carers. This was echoed by a few others who had looked – they felt that medication information could be found but information for carers/support was less good.

## 4.6 Rating of CAPCIS

Many people found the CAPCIS site to be visually appealing, largely based upon the colour scheme used and the flower motif.

*"It looks cheery, quite eye catching."*

However, others felt that it was too text heavy and needed to be broken up more for people to take the information in properly. The home page was described as particularly *"busy"* by some participants, which was off-putting. Others found the site to be easy to navigate and to have a lot of useful information (albeit that they were mostly just having a quick look prior to the focus group discussion and none were regular users) – *"it's what I would expect to see there"*.

A 'good' website was considered to be one which was eye-catching, colourful, not text heavy, not too official or serious, and an easy read.

There are obviously physical accessibility issues to consider, but participants were also conscious of the perceived inaccessibility of the name CAPCIS. It was not perceived to be clear in terms of what it means and, even when explained, it was not considered to convey the actual content of the site as palliative care was so closely linked with cancer rather than the progressive, life-limiting conditions it also covers. Once the content was explained, the majority of participants considered that there were benefits in co-locating information for sufferers/carers of cancer and progressive, life-limiting conditions but there needs to be greater clarity on what the site covers.

The name was perceived to be a real barrier to people finding the site – *"I would never have found it"*. If heard verbally, the spelling was perceived to be an issue as people felt they would be likely to try CAPKISS or CAPSIS.

Language is a key issue to consider in terms of accessibility as, for example, 'progressive, life-limiting condition' is *"not words people would actually use"*. A specific list at the side, of which cancer was only one condition, was seen to be more appropriate, in addition to using words like *"continuing conditions"*, *"continuing care"*, *comfortable"*, *"pain relief"*, *"aids and adaptations"* and *"quality of life"*.

It was suggested by a number of focus groups that they would not think the site was for them (non-cancer related) given the information on the home page, so that needs to be much clearer to get people to follow the links to information which might help: *"I'd have been straight back to Google if I saw that – it's all about cancer!"*

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The term 'palliative care' was also perceived to be quite frightening as it is seen to be "about dying", so this may not be the best term to use.

The CAPCIS site was perceived to have credibility on the basis of its clear links to the NHS. This was perceived to engender trust in the information provided.

Links to other sites were rated as being very important, to enable people to get the information they need directly. The fact that these have a brief description was rated positively by participants. However, participants felt that they could waste a lot of time following links which might not be relevant to them, so a bit more information on CAPCIS or a flow chart to summarise information was suggested as being useful.

It was suggested by participants that the blogs/fora were not used as people preferred to get in touch with organisations or people directly rather than using this medium. If there is to be some on-site discussion forum, then it was suggested that people would find it difficult to initiate things but may respond to topics started off by others, i.e. CAPCIS staff. Young people were perceived to be the most likely to participate in online discussions but the young people's group were not particularly strong users of this form of communication.

The fact that there are no adverts on the site was perceived positively, and the fact that the site is not a "commercial organisation like Google".

The range of cancers and conditions on which information was provided was perceived positively, but there were other conditions which people would like to see information on, e.g. diabetes as this was considered to be progressive if not treated properly, asthma, etc.

#### **4.7 Suggestions for improvement**

Given that the majority of participants paid attention to what their consultant or GP told them, referral to CAPCIS by GPs and consultants could make a tremendous difference in terms of awareness levels and usage. This was also perceived to be important as it can be difficult to remember to ask questions when attending an appointment, when hearing news that was unexpected or when a lot of new information is being imparted (often not assisted by medical language).

It was perceived to be important that patients/carers could call someone if they needed more information, with freephone or 0845 numbers being preferred. It was suggested that CAPCIS should have a telephone number should anyone have any queries or prefer to access information in this way. This was perceived to be particularly important for families/carers as they often do not have a direct link to a patient's consultant and so "don't have anyone to talk to or ask questions of". Some ability to talk through specific issues would be beneficial. The 'quality' of person answering calls was seen to be particularly important, as people may be upset when they call. It was suggested that staff should be understanding, a good listener, have a good understanding of English and local accents (i.e. not an offshore call centre) and should be knowledgeable or able to get back to people if they did not have information immediately. This suggests the need for counselling skills.

Public places such as libraries, supermarkets, post offices, lunch clubs, tea rooms, etc., were suggested as more appropriate locations to reach a wider number of people, as only two people had seen CAPCIS leaflets.

Whilst it was perceived to be useful that there is a list of pharmacies on the site, it was suggested that this would be more useful if opening times were listed, and information provided on late/weekend/24 hour opening.

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Practical information would be useful to users, particularly those who find themselves to be carers with no experience of even some of the basic skills required, as the following quote illustrates:

*“Basic information on cooking etc might be useful. Practical tips... how not to put your back out when lifting! Some things might be common sense for some people, but even things like how to store medicines.”*

#### **4.8 Packaging cancer and progressive, life-limiting conditions together**

Cancer was perceived to be a serious issue but one which has a lot of resources committed to it in many ways. It was generally acknowledged to be useful to focus on non-cancer related information but the way in which other conditions are covered, i.e. under the heading of palliative care, was not well-liked as this was perceived to be confusing (as palliative care is most strongly linked to end of life cancer patient care).

On balance, it was considered to be useful to combine information on cancer and other conditions as needs are often shared by patients/carers of both, but the way in which the site is branded and explained needs to be improved. The name CAPCIS was perceived to focus on cancer alone and not other progressive, life-limiting conditions.

#### **4.9 Comparison to other sources of information**

Participants who used the internet tended to refer directly to the *“high profile”* websites of the main charities/associations with the condition in the name, e.g. to go directly to Cancerbackup. CAPCIS was not perceived to be clear on what it was about in this way and so less effective in this regard. However, CAPCIS was perceived by some to be more *“manageable”* as it does not have as much information as some of the other sites.

Breast Cancer Care was rated very highly as a website, as were the other main cancer charity sites. The majority of participants stated that they would be more likely to go directly to these sites than via CAPCIS and would probably have these sites on their ‘favourites’ list. The McMillan site was criticised as being *“awful – a blunt instrument”*.

However, it was suggested that NHS 24 had similar information online so CAPCIS was an unnecessary duplication of effort.

Participants were quite clear that CAPCIS could and should not be the only form of information available to patients and carers as so many people do not and will not access the internet, for a range of reasons. If the site is useful for some people and represents good value for money, then it was recommended that it is rolled out more widely. If not, participants were keen that resources were used more usefully in other ways. The fact that many older people do not use the internet and yet are more likely to be facing the issues the site aims to address was seen to be a fundamental flaw in the CAPCIS concept. Whilst the internet is becoming more popular, it was not perceived to be *“there yet”* for many people. People were considered to be one of two extremes – either competent in using the internet (in which case they would tend to be able to find the information they wish through search engines) or not keen to use it at all (in which case this is not the forum for them).

There are still issues around internet connectivity in some remote and rural parts of Argyll & Clyde. Participants cited a fixed number of broadband lines in areas like Colintraive (so if these are all being used then no-one can access broadband) and patchy access in other areas due to hills/distance from the exchange, etc.

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It was suggested at the Oban group that the NHS in Skye has a similar service to CAPCIS, which was rated highly.

#### **4.10 Other comments**

Whilst participants had not used the CAPCIS site much, if at all, themselves they were still keen that this sort of resource is provided for those who might be interested or prefer to access their information in this way, provided that it can be done cost-effectively. It was recognised that people's information needs would differ just as much as their preferences for accessing that information, so this needs to be taken into account by the NHS.

Support groups found it useful to see what information was held on their own group on CAPCIS and to compare this to others in the area. Local information was perceived to be useful to have to enable support groups to network and also for local people to be able to access them more readily (although there was surprise that the Helensburgh carers group was listed under Oban).

It was suggested by one participant that support should be more proactive, e.g. patients/carers receiving a call, perhaps from Social Work, once a month or so to check that they are okay and that they have all the information and support that they need.

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# 5 Results and discussion – stakeholder interviews

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## 5.1 Overview

A wide range of different stakeholders were invited to give their views as part of the evaluation, including the CAPCIS team, members of the steering group and members of the working group. Chairs of the steering group and working group were interviewed and remaining interviewees selected at random (as there were more potential stakeholder interviewees than required). Stakeholders' views are reflected below under key themes explored in discussions.

## 5.2 Awareness and knowledge of CAPCIS

The CAPCIS team felt that awareness of the site was good. However, where other stakeholders had a view on awareness levels they were perceived to be poor, and others were unsure. Professionals who were consulted as part of the stakeholder interview process did not use the site, although they had looked at it prior to the interview. There was not a view that the site was well known, well-used or that health professionals would refer patients and carers to the website as there are other forms of information, people often prefer leaflets or face to face delivery of information and those working in health are often extremely pushed for time.

## 5.3 Rating of CAPCIS website

### 5.3.1 As an information resource

Stakeholders generally rated the site highly as an information resource for the target groups. However, it must be noted that these opinions appeared to rest, on the whole, on stakeholders having looked at the site prior to interview and thinking it looked “nice” (excluding the CAPCIS team, obviously) rather than on regular use of the site. Stakeholders were largely unable to comment on specific issues for each of the target groups (people with cancer, people with progressive, life-limiting conditions, informal carers, health professionals and young people) regarding the site as an information resource. The CAPCIS approach is to provide more general information, but some stakeholders would like to see more practical, detailed information for patients which they would not find on other sites.

The majority of stakeholders considered that it is useful to have information on the internet for those who wish to access information in that way, as internet usage is growing and is seen to be the medium of the future. However, it was clearly perceived to be one method of getting information to people rather than the sole means of communicating with people. It was perceived to play a role in providing information at times of day when other services are not open and it was recognised that some preferred to seek information themselves rather than ask a health professional or family member.

### 5.3.2 Accessibility and design

The site was generally perceived to be easy to navigate around and to look good.

*“It looks very nice – simple, attractive, not medical looking. The flowers are natural and hope inspiring. It doesn’t look like the NHS.”*

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It was presumed by stakeholders that the site had been equality impact assessed but some stakeholders were not aware of whether this had taken place or not. For example, whether the team have considered the site becoming Browsealoud enabled. The CAPCIS team have confirmed that the website is Browsealoud enabled, although it is noted that there is no notification of this on the accessibility information page and, when the site was searched for Browsealoud, it did not find any matches elsewhere on the site, so it is not explicit on the site. CAPCIS have also stated that the site has been tested with Opera Browser, which has improved accessibility features using voice and keyboard shortcuts. Again, neither of these were noted on the accessibility information page and could not be found elsewhere on the site.

It was viewed positively that there were specific sections for young people of different ages. However, the sections themselves were not considered to be particularly young person friendly, as they were not that different to the main site. More visual information and different language was perceived to be key to engaging with young people more successfully. It is noted that CAPCIS consulted CLIC Sargent, and other young cancer support/carer groups on the content of pages specifically for young people.

## **5.4 Strengths and weaknesses**

### **5.4.1 Strengths**

A strength of the CAPCIS website was that it was perceived to have information or access to information on a wide range of topics, backed as being “*valid and accurate*” as it was provided by the NHS. The information provided directly or indirectly was perceived to be useful information to patients and carers, particularly as it could be printed out (albeit with the caveats cited above).

The site is a portal to others providing information (who would therefore update their own information directly rather than CAPCIS having to do so) and this was perceived to be a strength. Stakeholders felt that replicating information would have been a duplication of effort and resources rather than adding value.

The site was perceived to be accessible and easy to navigate. It was perceived to be a “*quality*” site by some stakeholders as they liked the look of it and felt that it did not look like other NHS sites as it was “*warmer*”.

Palliative care information on non-cancer related conditions was perceived to highlight the need for end of life care in a range of contexts rather than just cancer. End of life cancer care was perceived to be the dominant societal understanding of palliative care.

Stakeholders felt it was useful that relevant information had been pulled together in one site. However, others felt that the site added little value in this regard as people who used the internet could easily search the internet for the information they sought.

The local support group information was seen to be a positive addition to the site as this is not necessarily easily found elsewhere.

The fact that the site promotes charities and conditions that the general public are less aware of was also perceived as a strength.

### **5.4.2 Weaknesses**

Low awareness of the site was perceived to be a key weakness, both amongst health professionals (who may use it directly or refer others to it) and patients/carers. There was a launch of the site but awareness of this was not universal amongst stakeholders interviewed. The degree to which the project has raised awareness of the site in non-

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NHS settings was queried by a stakeholder (a point which was also raised in focus groups) as, for example, libraries were perceived to be a good way to reach people (the example of the McMillan Project at Renfrew Library was cited). It is noted that the CAPCIS team did provide information to libraries, including the Renfrew Library, but awareness of this amongst both stakeholders and focus group participants was not high.

It was perceived to be disappointing that there are no entries on the blog or online fora on CAPCIS and suggested that CAPCIS should have initiated discussion themes to encourage people to participate as *“no-one wants to be first!”* The Patient Opinion site, established by a GP in Sheffield, was cited as an example to consider (as this is well used) as was greater promotion of the blog/fora generally.

It was recognised that CAPCIS does provide information but a lot of people prefer to talk to someone rather than look things up on a website and others do not have access to the internet. It was suggested that whilst there was some user involvement in the development of CAPCIS, greater involvement would have recognised that there is also a need to provide information or contact in different ways and this may have also influenced awareness raising/sustainability of awareness in order to encourage use issues. Whilst it was considered to be positive that some user views were gathered to inform the site, this was seen to be minimal, e.g. one visit to a group, rather than as inclusive and ongoing as it should be for a site of this nature.

There was a perception that the site was loaded more heavily towards cancer than other conditions. As palliative care is often associated with cancer, the CAPCIS name would not suggest to anyone (or appear on an internet search) that other conditions were included.

Whilst it was rated positively that there were separate sections for children and young people, these were not perceived to be very *“child-friendly”* as they did not provide information in a suitable/accessible format for younger people.

It was queried whether health professionals needed a website like CAPCIS as they have access to health related information via the Cochrane Library, for example, although it was recognised that it also provided access to information on benefits, voluntary sector support, etc.

Concerns were also expressed about whether information for professionals and members of the public should appear on the same website, in case members of the public misinterpret information, are concerned about information they read, or gain false hope or information about *“wonder drugs”* that aren't appropriate or available.

The fact that the website is designed externally rather than within NHS capacity was perceived to be a weakness as this was perceived to be a less efficient use of resources. It is noted from the CAPCIS team that working group members were trained in content management so they can update the website directly, although this was not highlighted by working group members.

In terms of those with progressive, life-limiting conditions who use the internet, it was suggested that they would already have access to alternative internet sites specific to their condition so CAPCIS would not add value to this group.

Some pages have a lot of information. Viewers have to scroll down pages and this was seen to be negative, as it is likely that relevant information will be missed. The CAPCIS team were conscious that people would like to see information on/recommendations for private sector services but, as part of the NHS, CAPCIS are not able to do this. The glossary could be improved (only 30 or so terms were included).

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## 5.5 Areas for improvement and challenges experienced

### 5.5.1 Suggestions for improvement

A key area for improvement was perceived to be raising awareness and usage, of the CAPCIS resource. This could be done in different ways, including raising awareness via non-NHS settings as outlined above, but Grampian CareData was cited as a good example of proactively raising awareness via free 'giveaways' such as pens, notepads and promotional events, etc. It was mooted that PC terminals in community health projects, community care forums, Social Work premises and libraries, with CAPCIS as the homepage would help to raise its profile. The launch and leaflets were seen to play a role in raising awareness but this requires continual reinforcement, particularly amongst professionals, to build a user base.

It was suggested that CAPCIS needs to raise awareness more specifically about the different ways in which health and care professionals can use the website resources, i.e. illustrating clearly the ways in which it can add value to their role, rather than assuming that staff will go away and look at the site and deduce exactly how it can help them.

Information in a format for people with learning disabilities was also suggested as an area which would improve the site, particularly as this information is often useful to others, e.g. young people, BME communities and Deaf people (as English language is often their second language).

There was concern about the veracity of a lot of information available on the internet and it was suggested that CAPCIS needs to do more to ensure that it is one of the first few sites selected by search engines such as Google, to guide people towards a reputable site rather than a commercial or misleading one. It was noted by more than one stakeholder that Capcis is an engineering company, so even if someone spells CAPCIS correctly when searching it does not come up as the number one hit. However, as noted earlier some people were unsure of the spelling of CAPCIS. This is a particular issue when relying on radio advertising as this is a verbal form of communication rather than written.

The CAPCIS name was seen to be associated most clearly with cancer and was perceived to be difficult to recall/understand. Palliative care, as a term, was also perceived to be open to misinterpretation and focus on cancer patients alone (although the site was perceived by some to counteract this, this was perceived to be the dominant societal understanding of palliative care). Several stakeholders felt that people often did not understand what palliative care meant. Clearer language needs to be used.

More information about usage was perceived to be important. For example, it was suggested that CAPCIS should look more closely at usage patterns such as how long pages are looked at and whether or not they are printed off, rather than overall usage rates. The CAPCIS working group suggested the number of unique users over the course of a month was perceived to be lower than the 3,000 suggested.

It was also suggested that more practical, detailed information should be provided. Suggestions included parking at hospitals (where, is it cash or tokens, etc.), what kind of staff will be caring for you and the roles they will perform, which pharmacies collect prescriptions from your doctor, etc.

It was suggested that there could be greater links with Social Work care and support services rather than the focus being solely on health.

There were some reservations about CAPCIS editorial processes – some contributors would like the information they provide to be taken as it stands, as coming from a reliable professional source, rather than being edited or censored in any way.

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It was suggested that CAPCIS could be used in other ways too, for example to link volunteer drivers and those needing their services, as transport is such a big issue for patients and their carers.

## **5.5.2 Challenges**

There were challenges at the start of the project as many organisations who could have been involved in the site did not see the need for it and saw it as competition rather than adding to what they do. The team felt that it took around a year in order to gain ownership for the concept of the CAPCIS site.

Getting the site off the ground within the timescales was perceived to be a particular challenge by the team. Three years was perceived to be "*just enough time*" to get things going and the budget has been under-spent, primarily due to lack of filled posts for part of the project period but no extensions are allowed by the Lottery.

The team have a much clearer idea of the way in which information needs to be collected, structured and displayed now and would design the organisational database differently if doing it again. It is suggested that any technical learning of this nature should be communicated to whoever takes forward CAPCIS, in whatever form, in future so that this is not lost.

## **5.6 CAPCIS structures and processes**

### **5.6.1 Working structures**

The majority of stakeholders have been involved as team, steering group or working group members. The steering group does not meet very often, once every six months, and has a relatively broad membership base. The steering group signed off the project plan, etc., at the start of the project and was thereafter kept up to date with progress. It was suggested that the steering group did not do much 'steering' as it does not meet often enough, participants are busy and there is little ownership of CAPCIS.

Whilst the working group was large on paper, comprising people from a wide range of disciplines, it was reported that attendance varied, with often only 5 or 6 people attending meetings. It was recognised that this presented challenges to the CAPCIS team in terms of moving things forward. Some stakeholders perceived there to be strong decision-making processes and a core group of attendees but others felt that the CAPCIS team made decisions and then 'consulted' the working group, which was considered to be inappropriate.

There was a view that there were some "*strong characters*" on the steering group but that there was a good mix of people on the working group. There were also mixed views on the degree to which steering and working group members felt valued and listened to – some were positive and others negative.

### **5.6.2 Resources**

CAPCIS was perceived to be a very strongly resourced project. Having vacancies within the team (the technical post was only recruited in June 2006 and admin support has been recruited more recently) has helped the financial performance of the project, so it will be under-spent on completion in November. Some stakeholders queried the need for all CAPCIS team members given that the web support is provided externally and working group members can update content directly. The value for money represented by the project, given its low usage rates, was also queried by some stakeholders.

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## 5.7 Comparison to other resources

Stakeholders were aware of the Glasgow based palliative care website, also funded by NOF. This was perceived by some to be aimed more towards professionals than members of the public, although it is clearly branded as providing a service to each.

Grampian CareData was cited as providing a similar online service – providing some information directly and signposting to others. However, this was seen to be much broader in scope than CAPCIS (more of a one stop shop for all health and community care needs). It had extra dimensions including a telephone helpline service to provide support to people who prefer to speak to a person, a research service to explore specific enquiries if they do not have the information on the website, a 'print off' service for individuals who require this function. These functions were valued by stakeholders in the CAPCIS evaluation.

The Cochrane Library and NHS e-library were also cited as resources for health professionals to use, albeit that it was recognised CAPCIS also provides non-health related information which may be of use to health professionals.

## 5.8 Future development

### 5.8.1 Cancer and progressive, life-limiting conditions

There were mixed views on whether all information should be housed on the one site or whether cancer was perceived to dominate CAPCIS. On balance, stakeholders felt that there were benefits in housing resources on different issues together provided this was done in an accessible way.

Those representing less common conditions were pleased to raise awareness of these within the CAPCIS website and it was considered to be important that palliative care is not just seen to be about cancer and “*end of life*”. The Scottish Executive were perceived to be promoting palliative care for non-malignant conditions more strongly. Where conditions are less common then it is more important that ‘transferable’ support for patients and carers can be found locally, as it is often not available to the degree that people might wish from national associations. However, there was concern that the close association between cancer and other conditions on the site might make those suffering from the progressive, life-limiting conditions listed worry that they may be at greater risk of cancer in some way. There were also concerns that cancer “*overshadowed*” other conditions as it is such a big and well-resourced issue.

The concerns about branding cited earlier should also be reiterated here – the name does appear to focus on cancer and the term palliative care is often understood to be purely about end of life specifically for cancer patients so, whilst there were recognised benefits in siting these together, people may not realise that non-cancer related information is there (either as people seeking information directly or health professionals directing patients/carers).

### 5.8.2 The future

There was real concern over the low usage rates of CAPCIS. If this is not addressed then the resource was considered to be a waste of money and that it would “*die*” anyway. It was recognised by stakeholders that the set up costs of CAPCIS would have been substantial but that maintenance would be less onerous. It was suggested that it would be a shame if it didn't continue because of that, as the “*hard work*” has been done. However, it was not seen to represent value for money given the level of funding the project has received, from those who expressed a view on this.

The key to any information support service was perceived to be involving users to ensure that it meets their needs as fully as possible. It is noted that a needs

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assessment was conducted early in the project's development but stakeholders were keen to see this continue to happen with CAPCIS or any successor facilities.

It was perceived to be key that any information resource should make it easy for users to find the information they were seeking and CAPCIS was perceived to be quite easy to navigate. The majority of stakeholders also felt that it is useful to have information gathered in one site, rather than patients or carers having to rely on a search engine, like Google, to find the information they need. This was not a unanimous view, however.

It was suggested that it makes sense to co-ordinate information resources for Greater Glasgow & Clyde, at least as this is now one health board area, but possibly extend this more widely to West of Scotland (for cancer resources as services are addressed on this geographic basis) or nationally for progressive, life-limiting conditions. The real benefits of broadening the basis of CAPCIS were perceived to be a more effective use of resources and greater clarity for patients and carers seeking information. More effective use of resources could result in the resource being extended in other useful ways, e.g. by providing a telephone helpline service. This includes a potential merging of the Palliative Care Glasgow site (and the Argyll & Clyde site presumably although this was not mentioned by anyone), which is also provided for both health professionals and members of the public.

Argyll & Clyde covers a large geographic part of the West of Scotland, so it was not considered to be unreasonable that the CAPCIS website is extended to cover the West of Scotland for cancer services, as services are provided on this geographic basis at present. Local support group information would require to be sourced to augment the existing Argyll & Clyde entries on the website. Other conditions are generally supported by groups or charities on a national basis, as these conditions are more rare, so may be more suited to national coverage.

It was noted that any expansion of the geographic area covered by CAPCIS would require a needs assessment in the first instance rather than assuming that people in other areas would just have the same information and support needs as residents of Argyll & Clyde. There may also be an issue around duplication of information/service as Lanarkshire, Ayrshire & Arran and Highland all have their own projects.

If CAPCIS is integrated with other websites, locally, regionally or nationally, stakeholders were keen that it retained its current look and feel, as this was rated positively. However, it was noted that any site funded by the NHS must look consistent with all NHS sites and this was not necessarily perceived to be a good thing.

## **5.9 Other comments or suggestions**

One stakeholder was keen that professional staff names were not given on the website, just contact numbers, as staff are not available 24/7 and the service should be publicised rather than the individual.

Some comment was made on links to international site, by more than one interviewee. The view expressed was that some international sites can provide valuable information and, provided an appropriate disclaimer is in place, this should be considered by CAPCIS. (The CAPCIS team report that this was a specific request of clinicians as US sites often contain information on drugs/treatment which are not available in the UK and/or have not been properly evaluated.) This also related to non-UK literature, as CAPCIS currently only cites UK literature but clinicians will use worldwide sources.

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# 6 Conclusion & recommendations

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## 6.1 Conclusion

The evaluation was commissioned to test awareness and usage of CAPCIS, whether the CAPCIS website meets the information needs of a range of different people: people with cancer; people with other progressive, life-limiting conditions; informal carers; health professionals; and young people. If not, to explore gaps and to gauge whether the internet was the best way of presenting information.

The website statistics would suggest that there are now on average just over 100 visits to the CAPCIS site per day, but there is no way of knowing whether users live or work in Argyll & Clyde. The response to the online survey was low, and only 61% were from Argyll & Clyde, which questions the veracity of logged visits and the site's success at reaching the target audience. Given the range of different people (patients, carers and health professionals associated with different conditions) this is not a high penetration of the target groups. Furthermore, despite a mix of methods and a lot of effort to involve support groups already targeted by the CAPCIS team, and a view amongst the team that awareness was high, the primary research conducted to assist in the evaluation of the CAPCIS website found very few people who had used the site and also very low levels of awareness of the site, even amongst internet users. It is acknowledged that target groups may not prioritise participation in research given other issues in their lives, however.

This would suggest that the project has been process driven in terms of getting a website up and running rather than outcome driven in terms of patients, carers and health professionals in Argyll & Clyde accessing a useful information resource which is adding value as a 'one stop shop'. For example, there is no identified risk in the action plan risk management section of low awareness or low usage rates and associated actions to militate against this. The project has been effective in setting up a web resource but is not yet as effective as it could be in terms of reaching its target audiences. It is acknowledged that timescales for the project have shortened, the website has only been operational for a year and the dissolution of NHS Argyll & Clyde will have had an impact on progress. However, marketing the website effectively should also be a key priority.

It is noted that the project team engaged in a range of different activities in order to raise awareness of/market the site. However, these cannot be seen to have been effective and the project underspend may more usefully have been spent in bringing in professional marketing/communications expertise to assist in this regard, as assistance was not available from NHSGGC. It is noted that the project team have also been conscious that funding is nearing an end and so have not been keen to raise awareness (and therefore expectations) more recently as the future of the site was unknown. Whilst this can be understood to a degree, it would not be recommended as a strategy to ensure a successful website and therefore future funding. It must also be noted that target groups for the CAPCIS website are not 'static', so marketing and awareness raising activity must be sustained.

Internet usage is still clearly not as widespread as the project might hope amongst the target group, as many participants in the focus groups did not have internet access or any interest in learning how to use the internet. Very few people cited the internet as their primary information source, as face to face communication (from GPs and consultants) and leaflets were generally more popular. That said, it does suit some people and it doesn't necessarily have to be a preferred or primary source of

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information to perform a useful function to some degree. It was recognised that the degree to which people wish to seek more information also varies as some wish to find out as much as they can whilst others do not.

The qualitative research would suggest that those who use the internet tend to use it regularly and are quite comfortable in doing so, or people do not use it at all. This questions the need for CAPCIS to bring information together, as participants tended to be comfortable in finding information from search engines such as Google or by going directly to a website. That said, some participants felt that it was useful that a locally-focussed resource was provided (although there is room for improvement in terms of providing practical local information).

Participants in the research gave a sense that they have had a quick look at the site rather than really used it, so they could not comment much around usage or whether key information was missing or not. The overall view was that it looked attractive but there are not many steps before passed to another site. There were questions as to what the money has been spent on because of this and there was a feeling that low usage rates implied poor value for money.

## **6.2 Recommendations**

Given that a substantial amount of money has already been invested in developing the CAPCIS resource, it would be unfortunate if this was now lost given that a little extra resource to ensure people know of it may result in higher usage rates and therefore positive outcomes for target groups. It is noted that it has been agreed that West of Scotland Cancer Network and Glasgow Palliative Care Network will take over CAPCIS once BLF funding ceases.

The research conducted for the evaluation would suggest the following specific recommendations for consideration:

- marketing activity should be reviewed and more effective means of raising awareness of CAPCIS amongst the target populations, e.g. particularly 'selling' it to consultants/GPs/other health care professionals as a means to add value to their role, as people listen to them;
- consideration should be given to changing the name 'CAPCIS' and the use of terms such as palliative care in order to be more accessible, clearer and to move away from the association of the term palliative with cancer only (this may also impact positively on it coming higher when people are searching for information via search engines);
- consumer testing could be more in-depth with target groups, e.g. young people, people from BME communities, people with different disabilities, etc., given some of the comments made;
- any work done to improve the accessibility of the site should be clearly notified on the information page so that those who might benefit from this, their carers and professionals know about this;
- local practical information could be provided, e.g. identifying which pharmacies pick up prescriptions, linking up volunteer drivers and those who need them, how to access aids & adaptations, who to go to for benefits advice and key questions to ask, etc., in addition to more information for carers;
- a telephone helpline would be welcomed by patients and carers as an alternative means of receiving information;
- if the blog is to be continued, members of the working group should initiate discussion on the blog to encourage others to participate;
- whilst the range of cancers/conditions was viewed positively, patients and carers would like to see this expanded; and
- consideration should be given to ways in which to gather more accurate data on website usage, to identify actual numbers and profile of users, gain insight into usage patterns and inform future development.