An investigation of cancer patients’ stories focussing on their interaction with CLAN service provision and multi-sector service provision.

Report of A Collaborative Research Project
CLAN Cancer Support and the IPE Research Team
Robert Gordon University & University of Aberdeen

2013
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1. Introduction

One in three people in the UK will develop some form of cancer in their lifetime. This results in 14,000 deaths in Scotland alone. 15,000 cancer diagnoses are made each year in Grampian with breast; lung and colorectal being the top three cancers by incidence across Scotland (NHS and ISD Scotland 2010). Costs for cancer treatment incurred in health and social care are increasing and policy driven joint working across sectors to share the burden of care and resources is a logical approach to adopt.

The cancer journey involves many different agencies and services working together to provide quality outcomes for service users and many of these are operating through CLAN premises. CLAN is one part of the support on offer to anyone affected by cancer. CLAN works closely with other charities, NHS and Local Authorities when supporting clients. Curriculum developers educating the future workforce should be cognisant that care and service delivery is managed by a number of agencies, namely, NHS, Social Services, Local Authorities; Voluntary and Independent sectors. Interprofessional curriculum development in Aberdeen embraces multi agency and interprofessional working and strives to involve the service user at the centre of its planning and delivery (Joseph et al 2012; Diack et al 2008).

Joint working between non-profit making organisations such as the education and voluntary sectors is seen as beneficial to the service user as the organisations share common values, concerns for the community and skill sets which can be shared (Huxham and Vangen 1996). Service users are the clients of many organisations and yet their views are not always sought. This report explains the underpinning of interprofessional education (IPE) in the development of a collaborative study with CLAN.

1.1 Interprofessional Education

This project was developed to complement ten years of the Interprofessional Education (IPE) programme established between the two universities in Aberdeen. The programme includes students from the following undergraduate courses: diagnostic radiography; dietetics; medicine; midwifery; nursing; nutrition; occupational therapy; pharmacy; physiotherapy and social work who learn together the skills of interprofessional working. The theoretical base for interprofessional learning can be found in many academic disciplines including sociology, psychology, anthropology, philosophy, and political sciences. Drawing on adult learning theories and engaging in life experiences, the aim is to develop independent learners and critical thinkers who have the ability to work interprofessionally by articulating their own professional requirements to one another in an environment of mutual respect and trust. The framework adopted for this pedagogy is adapted from Miller’s (1990) Taxonomy and the Centre for the Advancement of Interprofessional Education (CAIPE) definition.
A missing component from the IPE Aberdeen programme is a stronger link to the patient voice and this project helped address this omission. Importantly, the patient voice from the voluntary sector informing curriculum development for interprofessional education is unique within this proposal. Masters et al (2002) reported that there was a lack of active engagement by service users and carers in the development of the curriculum for nurse education. This refers to nurse education only and there is a dearth of literature relating to service user involvement in the interprofessional health and social care curriculum development in higher education. Whilst service users may be involved as part of the educational team developing the curricula for specific courses (e.g. nursing and social work) the researchers were unaware of previous projects that have attempted to introduce the patient voice from the voluntary sector into IPE curriculum.

1.2 The IPE Research Team

The IPE Research team conducted this research (see project team members- page 2). Their research mission was to:

“Provide evidence to underpin effective IPE teaching and lifelong learning equipping tomorrow’s practitioners with the intellectual capacity and desire to adopt innovative ways of working with other professionals to deliver quality patient/client care”.

The IPE research team have been involved in successful funding bids and public output, driving forward the evidence base for the IPE curriculum. A collaborative project between CLAN and IPE Aberdeen focussed on the existing strengths of both organisations with the potential to improve the integrated cancer patient journey.

The IPE research team met with CLAN’s executive group and agreed the project aim and design. It was apparent that there was common ground and much enthusiasm between the organisations to ensure successful completion. The implications for the dissemination of the project outcomes were seen as far reaching and potentially impacting the future working of CLAN and the education of health and social care professionals. The IPE research team was joined by the CLAN services manager who provided support and guidance throughout.

Table 1 depicts the goals and potential impacts that were identified for both organisations:
Table 1 Project Goals and Impacts

<table>
<thead>
<tr>
<th>Goal</th>
<th>Impact</th>
</tr>
</thead>
<tbody>
<tr>
<td>CLAN wished to gain an in-depth appraisal of the impact on service users of CLAN’s current service provision</td>
<td>Enable identification of areas of focus for service improvement and expansion.</td>
</tr>
<tr>
<td>Aberdeen IPE programme will benefit from gaining the views of service users on their experiences of multi-agency involvement in their cancer journey</td>
<td>Achieving this would enable the Aberdeen IPE programme to be informed by service users, more discerning of its educational focus and inform the IPE curriculum development when preparing tomorrow’s workforce.</td>
</tr>
</tbody>
</table>

A collaborative research project to achieve these goals for both CLAN and Aberdeen IPE was proposed between two organisations for the benefit of service users.

1.3 Aim

A pilot project was proposed to investigate the narratives of journeys that cancer patients and their families experience. The project focussed on the nature and scope of concurrent engagement with services from different agencies by service users. These agencies included the NHS, social services, local authority, voluntary, private and independent sectors.

The findings from this pilot project informed a proposal for a collaborative EU grant application for a larger scale project. However at the time of writing this application has been unsuccessful and other funding bodies will be approached for a large scale project.

1.4 Research Questions

The following research questions were identified:

1. What is the experience of multi-sector service provision for cancer patients and their families in the Grampian area?

2. In relation to the multi-sector service provision for cancer patients what impact does CLAN service provision have on cancer patients’ journeys?

3. Do service users perceive there to be gaps in multi-sector service provision, including non-statutory services i.e. CLAN and what impact does this have on cancer patients’ journeys and those of their families?
2. Study Design and Methods

Planning for the project began in autumn 2012 and a qualitative study using focus group methodology commenced in April 2013.

CLAN had an existing number of support groups which were used as the sampling frame. Participants from the following groups were invited to engage in ‘listening wall’ focus groups at CLAN premises. This method was adapted from Parsell’s ‘talking wall’ focus groups (Parsell, Gibbs and Bligh 1998). The ‘talking wall’ approach consists of facilitator led focus groups using post it notes written by participants and attached to flipcharts with specific headings. This project explored the narratives of patients and their relatives at various stages of the cancer journey. Therefore the research team explored ways to enrich the data gathered. This was achieved by modifying the talking wall approach and implementing a ‘listening wall’ approach. This method enabled facilitators to actively listen to the narratives of the participants and also enabled the participants to listen and respond to each other’s narratives. The facilitators guided the focus groups using a structured interview schedule to trigger discussion and participation (see appendix 3).

There were three phases to the focus group implementation:

- a brief verbal outline of their journey as an introduction to the group
- pictorial diagrams of participants’ cancer journey
- specific questions eliciting deeper insights into their narratives and discussion with facilitators and other participants (See Appendix 3).

Students participating in “talking wall” focus groups

The IPE research team undertook responsibility for the transcription of the material from the focus groups. Data from the post it notes were collated into an EXCEL file, the visual representations of the cancer journey were scanned for ease of analysis and the researchers wrote reflective notes of their facilitation experiences.

2.1 Recruitment

A convenience sampling approach was used by the team to recruit participants and CLAN’s existing support groups were targeted. These included cancer patients, cancer survivors, carers and bereaved relatives.
These target groups included Skin Cancer Group; Brain tumour group; UCAN group (Urology cancer); FAB (Friends after bereavement) group; PINK (People in Need of Kindness); Craft groups.

Five focus groups were planned comprising consenting members of these existing CLAN groups. However the first focus group did not occur due to low numbers and four focus groups were implemented. Posters and flyers inviting CLAN clients to participate were advertised in CLAN premises. Client information letters were given to all respondents to self select their day of attendance and also to gain their informed consent (See Appendix 1 and 2)

2.2 Ethics
The Grampian NHS Ethics committee were consulted regarding this project and they agreed that NHS ethics was not required as the research did not involve NHS patients or NHS premises. However ethical permission was sought and granted from the Robert Gordon University research ethics sub-committee. Due to the emotive nature of the research topic provision was made by CLAN to have additional support workers available during the focus group sessions and participants were informed of this at the start.

2.3 Data Protection
No identifiable participant data (names, codes) were recorded. All research materials were securely stored at RGU with access limited to the research team. All electronic files were held on the RGU H:/ drive, which is a password protected network. Transcription took place promptly after the focus group in a secure environment (not overseen). Printed materials (transcripts, cancer journey drawings) were stored in locked cabinets and only removed briefly for data entry in a secure environment. Sampling lists, records of participant consent and any return slips featuring names were securely stored, separate from all other research data to prevent identification through cross referencing. On recruitment, each group was assigned an identifying code and referred to by that code throughout e.g. in transcripts, publications, etc. Individuals in the group were not referred to by name.

3. Findings
Numerical and demographic data are summarised in Table 2

Table 2 Project Summary

<table>
<thead>
<tr>
<th>Project team members</th>
<th>Focus Groups</th>
<th>Participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total=7</td>
<td>53 responded</td>
<td>Those who had lost</td>
</tr>
<tr>
<td>Different professions</td>
<td>44 attended</td>
<td>Cancers: breast, bowel,</td>
</tr>
<tr>
<td>From two universities</td>
<td>Males=11 Females=25</td>
<td></td>
</tr>
<tr>
<td>&amp; CLAN</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total = 4</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Timings 2pm; 10am;12pm;10am</td>
<td>Group 1= 14 attendees</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Group 2= 7 attendees</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Group 3= 14 attendees</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Group 4 = 9 attendees</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Facilitators=two different</td>
<td></td>
</tr>
<tr>
<td></td>
<td>IPE Research Team</td>
<td></td>
</tr>
<tr>
<td></td>
<td>members per group</td>
<td></td>
</tr>
</tbody>
</table>
3.1 Phase 1
Participants introduced themselves to the group by stating their first name and a short description of their cancer experience so far. This allowed the participants to hear and empathise with their focus group peers and begin to deepen the narrative. The facilitators required skill to prompt participants in beginning to tell their story and at other times to restrict participants from detailing the entire journey during this introductory phase. The depth of detail that was presented was surprising to the research team who had been concerned that patients and carers might find this type of in depth discussion too emotionally draining.

3.2 Phase 2
To begin the discussion and commence the more discursive part of the focus groups the participants were invited to reflect their cancer experiences in a pictorial diagram. Some participants found this difficult and asked to be excluded from this. If preferred they could try and portray their journey in textual format but were not forced to do this in any way. Those who did participate in this exercise produced some valuable data that reflected a range of aspects pertaining to their journeys.

The images and text were analysed using an adaptation of De Bono’s six thinking hats (De Bono 1999) where the colours white, yellow, black, red, green and blue were used to decipher the ‘thinking styles’ within the data (See Appendix 3). Table 3 highlights the characteristics of the analysis.

### Table 3 De Bono Analysis of focus group images

<table>
<thead>
<tr>
<th>Colour</th>
<th>Characteristic</th>
<th>Related Comments</th>
<th>Explanation/Quotes</th>
</tr>
</thead>
<tbody>
<tr>
<td>White</td>
<td>Facts</td>
<td>Dates/times/diagnosis/treatment regimes</td>
<td>Statements and/or diagrams</td>
</tr>
<tr>
<td>Yellow</td>
<td>Optimism and positive thoughts</td>
<td>Healthy and well/systems and services that worked well</td>
<td>“Now much stronger as time goes on” “All treatment from diagnosis to death was excellent”</td>
</tr>
<tr>
<td>Black</td>
<td>Judgements and decisions</td>
<td>Diagnosis/surgery/types of cancers/stages of cancer/operative or not/inconclusive results/family history/GP,hospital,clinics/all clear/travel for treatment/self-fulfilling roles</td>
<td>“I was told that….“ “My five daughters were tested…..” Surgery performed “became a local coordinator”</td>
</tr>
<tr>
<td>Red</td>
<td>Feelings and emotions</td>
<td>Symptoms/happy or unhappy/progression of disease/lack of normality waiting times/travelling and costs/lack of competence/misdiagnosis/waiting times/effect on family/errors in appointment times</td>
<td>“Pain/tiredness/hair loss/unwell/side effects” “Shock/depression/dying and bereavement” No support Lack of professional competence/communication errors</td>
</tr>
<tr>
<td>Green</td>
<td>New concepts/creativity/new ideas</td>
<td>Resilience/perseverance/purpose CLAN/volunteering/complementary therapies/</td>
<td>Creating &amp; joining support groups Undertaking volunteering</td>
</tr>
</tbody>
</table>
### 3.3 Phase 3 CLAN Voices: ‘my cancer journey’

Four focus groups comprising people with personal experience of cancer (as either patients, partners, parents or carers) were held in CLAN premises during April – May 2013. Participants explored their cancer journey with particular reference to the way in which those involved impacted on their care and management. They responded to questions regarding what worked well and what did not work well in relation to the different professionals and organisations involved at various stages of their cancer journey. The stages of their journey were defined as Before Diagnosis; At Diagnosis; Since Diagnosis; Where they were now in their journey and Any other comments.

The themes identified are summarised in sections 3.4-3.6. The detailed analysis is found in Appendices 5-8.

#### 3.4 Key themes

Two key themes emerged from the analysis of the four focus groups and these were: The System and The Practitioners.

Table 4 highlights positive and negative responses for both the themes of the system and the practitioners at each stage of the journey.
### Table 4 Summary of key themes

<table>
<thead>
<tr>
<th>Stages of Journey</th>
<th>The System</th>
<th>The Practitioners</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Before diagnosis</strong></td>
<td>'GP acted very promptly and referred me to hospital without delay’ ‘Too long to wait for some test results. Long time to wait for treatments to be given.’</td>
<td>'GP was brilliant, didn’t panic me but arranged the appointment as a priority. She always made me feel that my care was a priority’. 'I was going to my local GP for almost a year before I was diagnosed. I was told there was nothing wrong with me... made to feel totally paranoid’.</td>
</tr>
<tr>
<td><strong>At diagnosis</strong></td>
<td>'Taken to a small room and told I had cancer, wife was also there.’ 'Post surgery diagnosis. Surgeon told me 6 weeks after surgery that the mass was malignant.’</td>
<td>Breast care nurses were very good, Responsive, available, good information. Consultant had time - not rushed. 'Consultant was very blunt. Nurses were more worried about my mother and I felt like I wasn't there.’</td>
</tr>
<tr>
<td><strong>Since Diagnosis</strong></td>
<td>'Chemo centre people were amazing, also the people at the radiotherapy department’ ‘Trying to get an appointment for a scan, I was told the Dr was on holiday! Not a good response’.</td>
<td>'Continuity of seeing the same consultant all the way from the first referral appointment. He also carried out the surgery. I felt I was treated as a person and not a patient with a bit of me needing to be cut away’. 'Surgery, non compassionate nurse. I felt like a body with no mind and no feeling’.</td>
</tr>
<tr>
<td><strong>Where are they now?</strong></td>
<td>'Following regular 3 monthly and now 6 monthly check ups, everything seems settled apart from lack of mobility of limbs’ '8 months on, waiting for appointment - have waited 5 months’</td>
<td>'Lots of support from ward staff, clinic staff, consultant very truthful and caring’ 'GP's lack of knowledge’ 'After treatment I realised I was on my own and had lost my safety net’</td>
</tr>
<tr>
<td><strong>Other comments</strong></td>
<td>Care in the community was good, allowed mother to be home for a month before dying. A follow up service AFTER treatment has ended is vital. Isolation and abandoned. 3 month check up idea.</td>
<td>At the end of my treatment I thanked my consultant and he said &quot;It was 50:50, you did half of it.&quot; Meaning I had looked after the wound and my body had done the healing up. Treatment is a partnership. Whole journey really been a battle with medical services. Voluntary support excellent. Could have been so much better.</td>
</tr>
</tbody>
</table>

Waiting times were often a criticism of the system throughout the journey. Whilst there were examples of effective services and practitioners who demonstrated exemplary performance there were others for whom this was not the case and this marred their cancer journey.

### 3.5 Other major themes

Whilst the two key themes of systems and practitioners were identified in all the stages of the cancer journeys there were other themes that occurred only at certain stages. Table 5 identifies these other themes and the stages they occurred.
Table 5 Other Major Themes identified for the stages of the journey

<table>
<thead>
<tr>
<th>Stages of Journey</th>
<th>Other major themes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Before diagnosis</td>
<td>Characteristics of the disease, Impact on life and living</td>
</tr>
<tr>
<td>At diagnosis</td>
<td>Shock, Other support services</td>
</tr>
<tr>
<td>Since Diagnosis</td>
<td>Other support services</td>
</tr>
<tr>
<td>Where are they now?</td>
<td>Impact on life and living</td>
</tr>
</tbody>
</table>

3.5.1 Characteristics of the disease
The theme ‘Characteristics of the disease’ was only identified in the ‘before diagnosis’ stage of the journey. In the early stages of their cancer journey several people had experienced symptoms and concerns that had eventually culminated in a diagnosis of cancer. Whilst some had legitimate grievances about failures in the system or clinical error delaying their diagnosis and treatment there were also experiences illustrating the difficulty in diagnosing the disease before the signs and symptoms became fully recognisable.

For example:
‘I was investigated for something else and had a tumour in my kidney – not malignant... Something told me there was something else. The year after I asked for another scan and it was then tumours were discovered in my bladder’

‘Had reflux and hiatus hernia. Had trouble swallowing. Went private for hernia operation. They looked down throat, oesophageal cancer found.’

For the other stages of the cancer journey key words were attributed to the characteristics of the disease as well as treatment and care. These are depicted in Figure 1.

Figure 1 Key words for theme characteristics of disease- for all stages of cancer journey
3.5.2 Impact on life and living
This theme was highlighted in two parts of the journey, namely: before diagnosis and where are they now?
Participants described their lives before diagnosis including the importance of ‘work’ and activity. For example:
‘Happy, healthy year. Out in the golf course…’ However, the ‘downward spiral, health loss and cancer spread’ clearly had a major impact on their lives.
At the ‘where are you now’ stage participants commented on how their journey had affected them as a consequence of their own or their partner’s cancer, frequently indicating emotional reactions and adjustments. For example: ‘Lost confidence during and after diagnosis’; ‘Personally - getting used to being alone’; ‘I am now at the bitter and angry stage’; ‘My cancer journey has given me courage I never knew I had’; ‘Although given the all clear, cancer is something that is always there. No mater how positive you are it’s always at the back of your mind’.

3.5.3 Shock
The 'At Diagnosis' stage identified the theme of ‘shock’. Although many of the groups felt supported there were some who highlighted shock at the time of diagnosis and felt that this could have been better understood by clinicians and that measures should be set in place to help them cope. For example: ‘Was hungry, lost confused and cold’; ‘Consultant or surgeon tells of cancer diagnosis then asks if you have any questions. How do they expect a patient to ask questions after this shock’; ‘After test were sent back to room and when door opened a whole host of people came in - very frightening’; ‘In shock! Breast cancer- too long a time between diagnosis to actual treatment’.

3.5.4 Other Support Services
Three stages of the journey highlighted the theme of ‘other support services and it was noted that this theme was missing ‘Before Diagnosis’.
Given the context of the interviews carried out and the objectives of the study, it is not surprising that support from CLAN and Macmillan was mentioned but more often from the diagnosis phase onwards. Table 6 highlights the comments regarding CLAN support at each stage of the journey.
Table 6 Comments regarding CLAN support

<table>
<thead>
<tr>
<th>Before Diagnosis</th>
<th>No Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>At Diagnosis</td>
<td>CLAN treatments first class and make you feel good; Cancer nurse was brilliant, very supportive - told me about CLAN</td>
</tr>
<tr>
<td>Since Diagnosis</td>
<td>CLAN; CLAN do a wonderful job; CLAN support therapies enhanced wellbeing; Compassion in the NHS - should come to CLAN for training; CLAN counselling after diagnosis; Groups that helped us: CLAN, Horizons, Brain Injury Group. Momentum; CLAN has been a great help to me in the last 5 years; Connection with CLAN for relaxation and therapies was very helpful. Professionals at hospital should suggest visit to CLAN when discharged from hospital;</td>
</tr>
<tr>
<td>Where are you now?</td>
<td>CLAN have been there for me and my child; On going support from local CLAN and on going co-ordinator; CLAN; Coming to CLAN for counselling; Finished treatment, quite healthy. Coming to CLAN really helps with confidence and support; CLAN very helpful - talk to people with cancer; Regular reflexology treatments at CLAN - providing total relaxation and the knowledge that advice is at hand; Working to support people and their families through my support Group and CLAN; CLAN at Stonehaven got me through the worst of the early stages and still help a lot</td>
</tr>
</tbody>
</table>

Apart from CLAN the following sources were mentioned as positively supporting their journeys:
Anchor Unit
Brain Injury Group
Chemotherapy unit
Clinic staff
Epilepsy clinic
Family Friends
Horizons
Lymphoma association
Macmillan Nurses
Macmillan Telephone support
Maggie’s Dundee
Momentum
Other Patients
Radiotherapy department
Roxburghe House
Ward staff

3.6 Other comments

These comments have looked at the journey overall and can be broadly summarised under two main themes: “aspects that worked”, “aspects that didn’t work”.

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3.6.1 Aspects that worked

There were many positive comments about treatment and care received. These included the partnership working between patients and consultants. Exemplary care in the primary and secondary sectors was mentioned including care in the community and in patient hospital experiences and outpatient radiotherapy services.

“All professions and nurses deserve a medal. Exemplary attention by all (even the cleaners and trolley people)”.

3.6.2 Aspects that did not work

There were criticisms of the medical services that included a lack of consistency of health professionals during the journey. Respondents much preferred seeing the same consultant each visit and differentiated between those who were ‘good’ and those whom they preferred not to see.

“Great consultant! It would help if you saw the same consultant every time you have an appointment. I always ask for him”.

There were communication issues that marred their cancer journey and they felt there were unnecessary long periods of time spent waiting for their results “from all departments”. These were attributed to communication delays often due to failings in communication processes and the lack of use of modern technology i.e. doctors waiting for postal services when e mail is available. This led to a great deal of anxiety in what was already a difficult and painful journey.

There was a perception of compartmentalisation during their journey that led them to feel that the services were not seamless and boundaries between services and organisations could not be easily crossed “no joined-up-ness”. Social services staff resources were criticised, “dire shortage of carers to come in on a daily basis from social services”.

A few participants vocalised unresolved issues of loss and bereavement and this suggested that they were not coping as well as others.

“Angry at lost life. Have to start a new life”

“Bitter and angry I won’t see grow up into the wonderful men they will become. I won’t be their for engagements, weddings and grandchildren. I love my boys so so much and I am so angry and bitter this is happening to them. This won’t make them stronger as someone once said. How can this battle make someone stronger? It does change you and not necessarily for the better. Thank you CLAN for all the support you have given us and continue to give”.

There was often support within the group for these expressions of anger and the participants ‘managed’ each others issues for the duration of the focus group. Researchers were concerned about these types of issues and advised individuals to partake of the extra volunteer support that had been arranged during and immediately after the focus groups if they so wished.
One individual spoke of her frustration when trying to care for her family member and being refused information due to data protection issues: "Data protection and confidentiality can sometimes get in the way of information that families need to care for the patient”

3.6.3 Improvements to the services
In addition to detailing ‘what didn’t work’ participants also made some recommendations for improving the services. These included a desire to ensure the communication relating to ‘clinical results’ process improved in efficiency. Dietetics follow-up especially after bowel surgery was seen to be important. The availability of supports services literature was also recommended as important within patient areas.

There were comments regarding the training of staff and they can be considered broadly into two areas. One was being the lack of time available for staff training even though this was desirable and the lack of acknowledgement of patient competence in understanding their own bodies.

The following two comments illustrate this:
"Nursing staff in a specialist area may wish to get further training but cannot have off the job training if staff shortages prevent the provision of cover”. "The hospital nurse took care of me right after surgery insisted on putting the oxygen tubing in my nose even after I repeatedly told her I was a mouth breather due to birth defects in my nose. She told me to leave the tubing alone or she would tape it into place. I asked for a mask and she said no, I had to have the tubing alone and to leave it alone. I hope I didn't need the oxygen because I didn't get any”.

Some participants also commented on the value of the research project for themselves to express these thoughts and also in the longer term to make a difference to future patient care. Whilst most enjoyed the group experience one comment related to preferring a ‘one to one’ experience to narrate their story.

4. Researcher Reflections of Focus Groups
The focus groups were not audio-recorded. In hindsight the facilitators reflected on how audio-recording might have impacted on the project and the group interaction. Most agreed that it could have potentially prevented the depth of sharing that was achieved. However the project’s outcomes critically lay with the facilitators’ perspectives and the content of the ‘post-it notes’. Therefore these researcher reflections are of paramount importance. The main themes extrapolated are organisational; starting out; group interaction; outcomes and conclusions.

4.1 Organisational
All the focus groups had male and female participants comprising patients; survivors; carers as well as spouses and parents who had experienced loss and bereavement. There were a number of different cancers and CLAN groups represented.
Facilitators followed the focus group schedule and prompted as appropriate. The setting was a round table arrangement where participants sat together for most of the discussion and moved around flipcharts on the surrounding walls. Only one group separated into smaller groups for part of the discussion. Refreshments were provided by CLAN at all the groups and RGU provided a sandwich lunch for the 12midday group.

4.2 Starting Out
The introductory session often took a longer than anticipated time as participants felt the need to expand on their cancer stories. In general facilitators allowed this to occur naturally with gentle reminders and ‘prompts’ to move on. The ice breaker followed the initial introductions and involved creating a ‘drawing’ of the cancer journey they had experienced. Some adapted to this more readily than others and one or two declined to do this preferring to verbalise their views. There was clarification on the scope of this activity by the facilitators and participants were invited to use ‘stick men’ drawings or text as they wished. It was also important to clarify that whilst we wished to know the professions involved we did not require names and locations. There were many varied and enlightening representations of the cancer journey through this activity. A few had written down their thoughts prior to coming to the group and had brought this with them and were happy for the facilitators to retain them.

4.3 Group Interaction
The participants generally found the methodology of the ‘listening wall’ easy to understand with periodical prompts to write on their ‘post- its’. Sometimes some were speaking their story whilst others were writing. In each group facilitators noted more vocal participants, quieter shy participants and those who preferred to write things down. On occasion the focus group was slower to start till the participants were acquainted with the style of it. Generally there was empathy for the stories with tears, laughter and participants were very attentive to the stories being told. There was empathy towards the accounts during the introductory session and participants recollected similar perspectives. There was a good flow of conversation and most groups were high pitched and emotionally charged. One participant had not cried before the focus group. Trust and mutual respect was demonstrated within the groups as participants shared intimately. Post diagnosis stories were often calmer and groups were quieter. These groups required skilled steering by the facilitators. The groups also became ‘self-helping’ in that the participants began comforting one another. One participant explained a spiritual dimension to his journey and another gave the group useful information about travel insurance companies for those with cancer diagnoses.

4.4 Specific concerns
The long wait for results at the early stages of their journeys was commonly reported. There were also perceptions that different cancers received different levels of service with unsurpassed services for breast cancer compared to prostate cancer. Care was not seen to be
individualised and participants expressed a need for this in comparison to what many experienced and this was ‘boxed’ care. A few reported negative experiences if they did not fit into a ‘box’. There was a perceived degree of ‘unpopularity’ if they asked questions. Some expressed a reluctance to be on the receiving end of too many treatment choices, preferring the ‘expert’ to make these choices for them. For others there was a clear expectation that they would be provided with detailed information on treatment choices and they would have input to deciding their own treatment. There were expressions of unresolved anger when cancers had been misdiagnosed or diagnosis had been delayed and a reporting of unfair service provision from Macmillan Cancer Support.

4.5 Outcomes
There was an affirmation of positive achievement for the participants. They found it useful to talk about their stories and whilst there were support staff available in the CLAN ‘drop in’ centre only one or two participants availed themselves of this additional support and this was often for social rather than emotional reasons. They confirmed that they had met new people even though many had been involved in CLAN services for many years. There was high praise for CLAN and the support network it provided at a critical time for the participants and their families. Information regarding CLAN would be helpful from health professionals especially to allay concerns regarding their access to the services. There were positive stories of NHS service provision as well as the concerns highlighted. Social services and other agencies were not mentioned.

4.6 Summary of reflections
Facilitation of two larger groups proved challenging and nine was agreed to be a manageable number for the nature of the topic. It was difficult to deal fairly with the stories in the time available. Two researchers shared their own family experiences of cancer and others did not choose to do this. Either way it was an emotional experience for the researchers. There were questions raised as to whether the research questions had been adequately answered within this pilot study and whether the ‘post-it-notes’ had captured the wealth of data. It was obvious to the researchers that a larger in depth study was critical to moving forward.

5 Discussion
The key elements of the study will be discussed by addressing the research questions and how effectively these were answered by the study design and sample groups.

5.1 What is the experience of multi-sector service provision for cancer patients and their families in the Grampian area?

The pilot study provided only a snapshot of the experiences of patients and carers who were recruited through involvement with CLAN. Nevertheless, it was apparent from the data analysis that the experience of the participants was very mixed. Many stated that they had a positive experience of the health and social care services, however an equal proportion described negative experiences pertaining to the system and
the practitioners they had encountered. The perception was that certain cancers had more efficient service provision than others e.g. breast cancer compared to prostate cancer. Surprisingly there were very few encounters with services other than health care. Only one participant described social services resource issues in the provision of carers at home. There was a lack of evidence regarding other local authority services or other agencies. The voluntary sector services were positively stated as supporting services to healthcare. However where participants were experiencing difficulties with healthcare services the voluntary sector and in particular CLAN services became more critical for their support and well being. In this respect the question has been answered with reference to certain sectors of service provision. It raises the question as to whether the CLAN participants were representative of wider society who regularly encounter in particular other local authority services or whether indeed CLAN clientele are from a different societal demographic. Those who volunteered may also not have been truly representative of the wider population of CLAN clients.

5.2 In relation to the multi-sector service provision for cancer patients what impact does CLAN service provision have on cancer patients’ journeys?

There were many responses that favourably described CLAN services provision and the impact these services had on their lives. There were perceptions within the groups that CLAN provided adequately for patients, carers, spouses and parents. The manner in which the participants accessed the services changed as their journey progressed. Their access commenced ‘at diagnosis’ and their role was that of recipient of services both the complementary services and the emotional support services. This type of access progressed through the ‘since diagnosis’ stage. By the time they had reached a ‘settled’ stage of their journey they occupied (or were planning to occupy) promoting and fund raising roles.

5.3 Do service users perceive there to be gaps in multi-sector service provision, including non-statutory services i.e. CLAN and what impact does this have on cancer patients’ journeys and those of their families?

In relation to the healthcare services described by participants there were gaps perceived in the system of treatment and care as well as the role of practitioners. The majority felt that the waiting times they had experienced for diagnosis, investigations and results were not acceptable. They suggested improvements to these services including the introduction of technology for more effective communication systems between hospital and primary care and greater emphasis on follow up after the ‘all clear’ had been given. Certain ‘gaps’ in the systems related to the continuity of services and often these pertained to communication errors amongst the staff working to maintain the systems.

Equally the ‘practitioners’ were criticised for creating ‘gaps’ in service provision. These related to gaps in knowledge and skill levels in some
cases. There were also examples of participants feeling that their knowledge of changes to their bodies were not accepted by the professionals. As well as expecting professional knowledge and skill to be of a high standard, participants expressed the need to see the ‘human face’ of the professionals they encountered and in some instances this had not been the case. There was a sense of care being compartmentalised rather than individualised and this often correlated with professional behaviours that were not personable. There were also references to some cancers being different and not ‘fitting the box’ and this related in perceptions of being the ‘odd one out’.

As far as the non-statutory services, as mentioned previously these were accessed to a greater extent when the gaps in the health care systems were apparent. There were no gaps reported in CLAN service provision. Participants were able to access services in a timely and effective manner. In terms of awareness of services from voluntary organisations such as CLAN, participants did expect practitioners to provide the relevant information. Their experience of this was mixed and it was one area they felt improvements should occur.

6. Limitations of the study
This was a small scale pilot study that relied on a convenience sample of volunteers’ opinions on their cancer journeys. The motivation for their attendance at the focus group is not known and on recruitment they expressed their interest to share their stories. These participants could have an inherent bias in their views of the health and social care systems involved in their care and treatment. It was obvious to the researchers that there were unresolved issues for some of the participants. This study is a ‘snapshot’ of CLAN clients’ experiences. Researcher bias in conducting the listening wall focus groups was minimised by ensuring they worked together in different pairs each time. When analysing the data the researchers allocated the initial data to one of the team who had not participated in the focus group facilitation ensuring validity and reliability for theme development.

7. Conclusion
This study concludes by considering the planned goals and impacts.

7.1 CLAN wished to gain an in depth appraisal of the impact on service users of CLAN’s current service provision to enable identification of areas of focus for service improvement and expansion.

The reaction of the participants to CLAN service provision has been consistently positive and therefore there were no further improvement areas identified. However a more in-depth study with greater numbers of participants could explore this further. It would be interesting to compare CLAN clients’ perceptions of CLAN with those who not currently accessing CLAN.
7.2 Aberdeen IPE programme will benefit from gaining the views of service users on their experiences of multi-agency involvement in their cancer journey to enable the Aberdeen IPE programme to be informed by service users, more discerning of its educational focus and inform the IPE curriculum development when preparing tomorrow’s workforce.

This study has the potential to benefit IPE curriculum developers. The findings have focussed on the health care service provision and the importance of voluntary sector provision. These elements can be important additions to the curricula of health and social care courses.

8. Recommendations
The findings of this pilot study suggest that there is still more research to be undertaken and the project stakeholders consider the implications for their service provision. The main recommendations are:

- To make comparisons between the findings of this pilot study and Clan clients use of services.
- To seek resource for a comprehensive study with patient and carers experiences of multi-sector service provision.
- To develop the IPE curriculum to engage learners in enquiry into multi-sector service provision, teamworking and communication processes.
- To promote education and training for existing practitioners that reflect an equality of service for all cancer patients.
Appendix 1a Flyer inviting participants

An invitation to “make a difference”

t: 01224 647000
www.clanhouse.org

Have Your Say!
Share your experience of the cancer journey and help shape the training of future professionals.

CLAN is working with both Universities in Aberdeen to capture the experiences of clients who use the NHS, Social Care Services and CLAN.

To participate in our project, please pick up an information pack from your local service co-ordinator

CLAN
cancer support for all
An invitation to “make a difference”

Have Your Say! Share your experience of the cancer journey and help shape the training of future professionals.

CLAN is working with both Universities in Aberdeen to capture the experiences of clients who use the NHS, Social Care Services and CLAN.

To participate in our project, please pick up an information pack at reception.
Appendix 2 Information letter and consent form for focus group participants

The Cancer Journey – how your story/experience can influence service provision across the North East?

Dear CLAN client,

Thank you for reading this information leaflet.

We would like to invite you to participate in a joint research project led by Robert Gordon University and University of Aberdeen in collaboration with CLAN.

Our aim for the project is to understand what it is like to use services provided by the NHS; Social Care and the charity sector in the form of CLAN Cancer Support.

What you tell us will help to shape the education and training for future health and social care professionals, and help CLAN to understand more about the benefits of its service to you and your family.

It is important to continually improve the content of educational programmes and your contribution will help us make improvements in learning, and therefore improve the working practices of future health and social care professionals to the benefit of those diagnosed with cancer in the future.

You are invited to attend a focus group comprising of other clients from CLAN. We would really value your support and contribution to be a part of a focus group.

During this focus group we will ask you to tell us about your cancer journey and the people you met along the way. We are interested in how people (including professionals, family, friends and people in the charity sector like CLAN) worked with you and each other during your journey.

Each Focus Group will run for a maximum of two hours in CLAN’s premises, 120 Westburn Road, Aberdeen, AB25 2QA. Light refreshments will be provided.

Your anonymity and confidentiality are guaranteed and any information you give us that is specific to you and your experience will be generalised to ensure your privacy.

Your interest to participate is voluntary and you can change your mind about being involved at any time.

For further information please contact:

Dr. Sundari Joseph, Project Team Leader
Lecturer in Interprofessional Education
Room H310
Faculty of Health and Social Care
The Robert Gordon University
Garthdee Road
Aberdeen AB10 7QG  Tel: 01224 262975
e mail: s.joseph@rgu.ac.uk
Please complete this Reply Slip if you wish to participate in the study:

Name........................................................................................................

Contact Number....................................................................................

E mail........................................................................................................

If you are a member of a particular CLAN group please say which one:
........................................................................................................

The focus Groups are scheduled to run on the following times:

Thursday 11th April 2-4pm
Friday 19th April 2-4pm
Thursday 25th April 10-12pm
Wednesday 1st May 12-2pm
Monday 13th May 10-12pm

Venue:  CLAN House, 120 Westburn Road, Aberdeen, AB25 2QA

Once completed, please place in the attached addressed envelope and return to reception

Please complete and bring along with you to the Focus Group

Confirmation of consent to be collected at the focus group
(Two copies- one for participant and one for researcher)

Please complete the information below to participate in the project.

<table>
<thead>
<tr>
<th>Statement</th>
<th>Please write yes/no</th>
</tr>
</thead>
<tbody>
<tr>
<td>I have read the information letter regarding the project and am willing to participate fully.</td>
<td></td>
</tr>
<tr>
<td>I agree to participate in Focus Groups</td>
<td></td>
</tr>
<tr>
<td>I accept that confidentiality and anonymity will be guaranteed in the reporting of the study</td>
<td></td>
</tr>
<tr>
<td>I understand I can leave the study at anytime</td>
<td></td>
</tr>
</tbody>
</table>

Please print your name

Name.................................................................
Appendix 3  LISTENING WALL Approach

Listening Wall- focus groups
Dates and times
Thursday 11th April 2-4pm (cancelled due to lack of sufficient response)
Friday 19th April 2-4pm
Thursday 25th April 10-12pm
Wednesday 1st May 12-2pm or 2-4pm
Monday 13th May 10-12pm
Monday 13th May 12-2pm Project Team Meeting

Facilitator schedule

Set Up- Flipchart paper around the room- 7 places to stick paper required; Laminated headings; Post it notes; Marker Pens

Refreshments: Tea/coffee/water/biscuits. Lunch on 1st May

Two researchers per focus group from project team

Headers for flipchart:

Before Diagnosis
At Diagnosis
Since Diagnosis
Where are you now in your cancer journey?
Things that went well?
Things that didn’t go well?
In the future how would you wish people/team to be with regard to cancer care?

Preliminaries:
- Welcome and thank everyone for being there
- This is a research project.... Who we are? What we are trying to achieve?

Icebreaker
Draw a picture or diagram that represents the people and job roles involved in your cancer journey

Listening Wall
• This is a focus group with a listening wall approach- they will be invited to write information on ‘post it’ notes about their cancer journey and in particular about the team and people involved at different stages of their cancer journey. We are not audio recording any conversations.
• This information will remain confidential to the project team and will be anonymous. The data including their details will be kept locked at all times. Some quotes may be used to illustrate the findings of the project but will be anonymised and any identifying features will be removed.
• If they do not wish to share information they do not have to
• If they are upset in anyway- there are support staff who are available through CLAN
• The time is limited to 2 hours and we will stop at this point
• They are free to help themselves of refreshments at any time

**Prompts**

• We are interested in the individuals who have been involved in your journey through cancer and the way in which they may or may not have worked together with you and each other - but we require their job roles than their names
• We are interested in the organisations that have helped you along the way- especially CLAN
• What other organisations have been involved- e.g. NHS, Social Services; Other charities; education; police etc.
• Thinking about the people who have been there on your cancer journey (family, friends, health care professionals, Clan etc) and the way they supported you or worked with you, tell us about those things that went well?
• Thinking about the people who have been there on your cancer journey (family, friends, health care professionals, Clan etc) and the way they supported you or worked with you, tell us about those things that didn’t go well?

**Appendix 4 De Bono’s Six Thinking Hats adapted for analysis of focus group images**

• Facts/information were underlined in **white**
• Optimism and positive thoughts were underlined in **yellow**
• Judgement and decisions were underlined in **black**
• Feelings/ emotions were underlined in **red**
• New concepts/ creativity/ new ideas were underlined in **green**
• Phrases that expressed rationale/cause and effect were underlined in **blue**
Appendix 5 Analysis of Before Diagnosis Responses

Section 1: Before diagnosis

Participants identified key features from their experiences of what worked and what did not work at the start of their journey i.e. before diagnosis and posted these on the ‘listening wall’. These postings have been analysed below. Four main themes arose.

Theme 1: The System
The general consensus is that when the system works, it works well providing a good service and alleviating initial distress and concerns. However, when the system falls down this is seen to have significant effects on the mental and physical wellbeing of the cancer sufferer and their families.

Prompt referral and quick appointments were seen to be positive.
'GP acted very promptly and referred me to hospital without delay’ (FG1)
'Good treatment given when I first visited the health centre and given an early appointment for biopsy’ (FG1)

However, waiting was a common experience and seen as something that ‘didn’t work’ in their cancer journey.
'Long wait for results for biopsy, not good.’ (FG1)
'Too long to wait for some test results. Long time to wait for treatments to be given.’ (FG3)

Other participants felt that their diagnosis had been delayed by clinical or administrative errors. This participant felt that poor clinical judgement and system delays had resulted in receiving treatment too late.
'Two year delay in being referred by GP to surgery for diagnosis and investigations resulting in cancer, non-treatable.’ (FG4)
Another said
'Clinical error in the breast clinic delayed my initial appointment by three weeks.’ (FG2).

Sometimes it is not possible to tell whether a delay is due to poor service systems or the lack of communication with the patient. Whatever the reason, this had the potential to bring about uncertainty and anxiety.
'October 2009, large mole biopsy taken but no decision made at this point. Left waiting.’ (FG1)

Administrative errors were also noted.
'Doctor said OK – scope done. We went on holiday, case not followed up / handed over. Jan got letter saying cancer – shock.’ (FG3)
'Doctor discovered that something had shown up in the x-ray about ten years before but notes had been filed away without doctor seeing it.’ (FG4)

A quick diagnosis and efficiency were seen as beneficial
'Breast clinic great. Quick diagnosis.’ (FG4)
'Monogram clinic was excellent and efficient.’ (FG2)

This person felt the honest and upfront delivery of the diagnosis was important.
'Consultants, be upfront with patients; don’t sugar-coat it’ (FG1)

The thoroughness of investigations and tenacity of the hospital was appreciated.
Once the hospital got me, they didn’t let me go until I finally got the diagnosis. (I was) at hospital every week for tests /a scan / something else.’ (FG2)

One participant commented on the shock caused by the delivery of the diagnosis of cancer to their son.
‘Son being given the results by himself. Feel someone should have gone with him.’ (FG2)

The importance of appropriate information and knowledge delivered within the system was seen as reassuring and beneficial.
‘Given full accurate information, questions were answered which was reassuring.’ (FG2)

**Theme 2: The characteristics of the disease**

In the early stages of their cancer journey several people had experienced symptoms and concerns that had eventually culminated in a diagnosis of cancer. Whilst some had legitimate grievances about failures in the system or clinical error delaying their diagnosis and treatment there were also experiences illustrating the difficulty in diagnosis the disease before the signs and symptoms became fully recognisable.

Participants described their experiences.
‘Months before a full diagnosis. Lung cancer creeps up on you.’ (FG2)

Sometimes other conditions can mask the cancer and delay diagnosis.
‘I was investigated for something else and had a tumour in my kidney – not malignant… Something told me there was something else. The year after I asked for another scan and it was then tumours were discovered in my bladder’. (FG3)

‘Had reflex and hiatus hernia. Had trouble swallowing. Went private for hernia operation. They looked down throat, oesophageal cancer found.’ (FG4)

Frustration is obvious when people feel they are battling the system to be believed.
‘I had to ask for a scan, they said no and just gave me an x-ray. It showed there was a shadow.’ (FG1)

**Theme 3: Practitioners**

All focus groups returned responses in this category.

Perspectives varied about experiences of practitioners with views ranging from very positive to very discouraged.

The characteristics that participants described as ‘working’ included expertise, reassurance, prompt attention and working together.
Participants were positive about the ‘consultant’ (FG1), ‘very positive specialist nurses’ (FG2) and some interactions with their GP.
‘GP was brilliant, didn’t panic me but arranged the appointment as a priority. She always made me feel that my care was a priority.’ (FG2)

One person described how their GP’s good practice resulted in an appropriate hospital referral.
‘Visited GP to be told nothing to worry about... but as a precaution I would be sent to hospital’ (FG1)

One person gave an example of how good inter professional working led to a diagnosis.
'Optician picked up something, sent to ARI clinic where the scan brought the tumour to light.' (FG3)

However, not all participants reported positive experiences with clinicians. Facts and certainty as well as an appropriate manner seem to be necessary clinician traits. One participant felt their GP was 'non committal' (FG1) and other clinicians were described as having 'not a good attitude, too many opinions’ (FG1).

Several participants described situations where they felt they had not been believed or taken seriously.
'GP tend not to believe women between 35 – 50. It’s a battle.' (FG2)
'GP was disbelieving. Sent me to hospital to stop me worrying, did not see it as urgent.' (FG2)

Other participants felt they had received wrong or delayed diagnosis from their GPs.
'GP said it was a virus.' (FG3)
'I was going to my local GP for almost a year before I was diagnosed. I was told there was nothing wrong with me... made to feel totally paranoid.' (FG2)
'Too long to diagnose, it took 18 months. GP followed the wrong route.' (FG4)

One participant described how they had lost confidence in their clinicians.
'GPs were awful. Gynaecologists did not feel any abnormality until they were asked. They didn’t know what they are looking for.' (FG3)

**Theme 4: Impact on life and living**

Three focus groups returned response in this category. Participants described their lives before diagnosis including the importance of 'work' (FG1) and activity.
'Happy, healthy year. Out in the golf course...’ (FG4)
However, the 'downward spiral, health loss and cancer spread’ (FG4) noted by a participant in their partner was clearly a major impact on their lives.

**Appendix 6 Analysis of At diagnosis responses**

These comments can be broadly considered under three main themes: “the system”, “practitioners” and “other support sources”.

**Theme 1: The System**

There were many positive comments about how people received the news that they had cancer. A few of these gave te detail of how this happened. Usually in private and with a spouse or friend.
'Taken to a small room and told I had cancer, wife was also there.’

However, the vast majority of positive comments about the system were expressed in terms that highlighted particular groups of practitioners in these departments.

Amongst those comments that were more critical most were to do with people involved and the manner the patient was informed about the cancer. Most comments highlighted **lack of appropriate or timely diagnosis in direct contradiction of those who felt it worked well**:
Post surgery diagnosis. Surgeon told me 6 weeks after surgery that the mass was malignant.

Consultant was very blunt. Nurses were more worried about my mother and I felt like I wasn't there.

**Theme 2: Practitioners**

As mentioned above, there were numerous very positive comments about individual clinicians. These also spanned a range clinician groups and a range of positive attributes relating to attitudes, knowledge and practice:

*Breast care nurses were very good, Responsive, available, good information. Consultant had time - not rushed.*

However perceived problems with clinicians’ attitudes, knowledge and practice were also highlighted and in many cases seemed the exact opposite of those who had very positive experiences.

Consultant was very blunt. Nurses were more worried about my mother and I left like I wasn't there.

**Theme 3: Other Support Sources**

Given the context of the interviews we carried out and the objectives of the study, it is not surprising that support from CLAN and Macmillan was mentioned but more as potential sources during the diagnosis phase.

**Theme 4: Shock**

Although many of the groups felt supported some highlighted the shock at the time of diagnosis and felt that this could have been better understood by clinicians and that measures should be set in place to help them cope.

Was hungry, lost confused and cold

**Appendix 7 Analysis of Since diagnosis responses**

**Theme 1: The System**

There were many positive comments about treatment received since diagnosis. A few of these gave outline of a journey through services and departments:

"Chemo centre people were amazing, also the people at the radiotherapy department”.

However, the vast majority of positive comments about the system were expressed in terms that highlighted particular groups of clinicians in these departments (see “Clinicians” theme below).
Amongst those comments that were more critical of the system there were two sub-categories. Firstly there were comments that highlighted lack of timely access to the right advice/information/person/treatment:

“Trying to get an appointment for a scan, I was told the Dr was on holiday! Not a good response”.

“Didn’t get to speak to the doctor that gave me the diagnosis until 2 weeks later”

“No access to a clinical nerve specialist as skin cancer patients at Nine wells do. Regular attendance at support Groups at Maggie’s Dundee have convinced me of the value of the CNS”.

Secondly, there were critical comments that more specifically highlighted intra-system communication difficulties:

“Correspondence between departments, very slow”.

“Staff in a department not always speaking from the same hymn sheet. Thus advice not always correct”.

“Always changing or mixing up appointments for treatments”.

**Theme 2: Practitioners**

As mentioned above, there were numerous very positive comments about individual clinicians. These also spanned a range clinician groups and a range of positive attributes relating to attitudes, knowledge and practice:

“Continuity of seeing the same consultant all the way from the first referral appointment. He also carried out the surgery. I felt I was treated as a person and not a patient with a bit of me needing to be cut away”.

“Surgeons in intensive care and high dependency nurses were good quality”.

“The district nurse who came to see me was outstanding. She was never rushed an even took my bloods at home when I wasn’t strong enough to travel to hospital”.

“Occupational Therapy from Aboyne House was quite magnificent - could not have been more caring and helpful”.

“Psychologist at Roxburghe House helped and helped a lot with my emotional state”.

However perceived problems with clinicians’ attitudes, knowledge and practice were also highlighted:

“Surgery, non compassionate nurse. I felt like a body with no mind and no feeling”.

“MacMillan nurse did not seem to know about lymphoma, only saw her once”.

“My oncologist told me point blank that I would not be continuing with Mistletoe Therapy, nutritional therapy or anything other than what she said I could have. She told me I could take a vitamin pill but it wouldn’t do me any good. I carried
on with all of my other supplements and treatments and I feel that these things made a huge difference in my survival”.

More generally, one participant contrasted staff attitudes with those in CLAN:

“Compassion in the NHS - should come to CLAN for training”.

**Theme 3: Other Support Sources**

Given the context of the interviews we carried out and the objectives of the study, it is not surprising that support from CLAN featured very prominently and positively in this theme:

“CLAN support therapies enhanced wellbeing”.

“CLAN has been great. Somewhere to talk. Therapies are relaxing and therapeutic”.

“CLAN counselling after diagnosis”.

“Connection with CLAN for relaxation and therapies was very helpful. Professionals at hospital should suggest visit to CLAN when discharged from hospital”.

Several other sources of valued support were also highlighted:

“Used Lymphoma Association for information, telephone support”.

“Groups that helped us: CLAN, Horizons, Brain Injury Group. Momentum”.

“Family and friends very important in supporting me”.

The latter comment makes explicit an aspect that was often mentioned in passing, or implicit, in the discussions around the table during the interview process.

**Appendix 8 Analysis of responses to the question: Where are you now in your cancer journey?**

A significant number of the comments from the four focus groups relate to individuals’ experiences of follow up and support. In addition there are comments relating to the perhaps psychological adjustments that individuals have made during their journey. Regular check ups featured highly in this group and form the bulk of comments regarding ‘the system’:

**The system**

Regular follow up featured significantly in the responses of all four focus groups and in a number of instances indicate the ongoing journey which continues after discrete treatment and intervention have taken place.

“…Following regular 3 monthly and now 6 monthly check ups, everything seems settled apart from lack of mobility of limbs…”
“…Going back every 6 months to see surgeon and consultant…”

Whilst such follow up was commented on, there was a sub-category which emphasised the importance of the ongoing contact in terms of support and reassurance. Conversely, in one instance, a participant highlighted the sense of vulnerability in the absence of ongoing follow up.

“…We are at the stage that no treatment can be given but we are still getting support from other departments…”

“…Reassurance of regular check ups, usually by the consultant who performed the treatment. Very effective appointment system…”

“…Present on 6 month check ups. Feeling much stronger now and coping better…

“…Following regular 3 monthly and now 6 monthly check ups, everything seems settled apart from lack of mobility of limbs…”

“…After treatment I realised I was on my own and had lost my safety net…”

One participant indicated delays in the system:

“…8 months on, waiting for appointment due to abdominal issues and heavy periods - have waited 5 months..”

**Practitioners**

As in previous sections of the analysis, clinicians were commented on. One participant noted the positive supports offered by clinicians and beneficial characteristics

“…Lots of support from ward staff, clinic staff, consultant very truthful and caring…”

Conversely, however, one noted that the “…GP’s lack of knowledge…” caused concerns. ‘Clinic staff’ and ‘dentist’ were noted but with no further comment.

**Impact on Life and living**

Many participants commented on how their journey had affected them as a consequence of their own or their partner’s cancer, frequently indicating emotional reactions and adjustments.

“…Lost confidence during and after diagnosis…”

“…Personally - getting used to being alone…”

“…Angry…”

“…I am now at the bitter and angry stage…”

“…My cancer journey has given me courage I never knew I had....”

“…Although given the all clear, cancer is something that is always there. No matter how positive you are, it’s always at the back of your mind…”
“…Continuing to be positive in life despite my wife dying…”

One participant indicated that they had started a new business and hoped to take trips around the world.

**Supports**
Participants commented on the supports that they encountered, both from the Health Service but also from elsewhere:

“…CLAN have been there for me and my child…”

“…Finished treatment, quite healthy. Coming to CLAN really helps with confidence and support…”

“…Regular reflexology treatments at CLAN - providing total relaxation and the knowledge that advice is at hand…”

“…CLAN at Stonehaven got me through the worst of the early stages and still help a lot…”

“…Finished treatment, quite healthy. Coming to CLAN really helps with confidence and support…”

In addition, a number of participants mentioned additional therapies which they received from CLAN, specifically mistletoe therapy and reflexology. The knowledge that advice was at hand was commented on as was:

“…Working to support people and their families through my support Group and CLAN…”

**References:**

NHS and ISD Scotland 2010
http://www.isdscotland.org/
http://www.isdscotland.org/Health-Topics/Cancer/Publications/data-tables.asp?id=1079

DATA PROTECTION ACT 1998


JOSEPH, S. DIACK, L., HAXTON. J. AND MCFADYEN, M. 2012. Diversity in Interprofessional Education: Disciplines and Topics. All Together Better Health VI,
The 6th International Conference for Interprofessional Education and Collaborative Practice Exploring New Horizons: Diversity and Quality in Interprofessional Education and Collaborative Practice, 5th-8th October 2012, Kobe Gakuin University, Kobe, Japan.

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