



Research Article

# Users' Perceptions of Interprofessional Collaborative Care during their Cancer Journeys'

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## Abstract

**Purpose:** The study aimed to construct narratives of journeys that cancer patients and their families experience and to investigate participants' perceptions of related interagency collaboration spanning any engagements with the National Health Service (NHS); social services; local authority; voluntary; private and independent sectors. **Methods:** Using a qualitative design and focus groups the key facets of integrated care were explored with clients from a charity that focussed on cancer care. The 'talking wall' approach was adapted for use in the focus groups. Framework analysis was used to extrapolate the key themes. **Results:** Focus groups with 44 volunteers were conducted. Data included visual representations; textual comments and researcher reflections. The findings highlighted that the care received by many of the volunteers was variable with reports of very satisfactory experiences and also poor experiences. Respondents expected collaborative care and only in its absence was there cognisance of its importance in streamlining services for their care journeys. The role for the voluntary and independent sectors was significant. **Conclusions and Implications for cancer survivors:** Effective interprofessional collaboration was perceived to ease the pain of the cancer journey. The different yet interlocking interventions and support from statutory and voluntary agencies is clearly a holistic approach that is appreciated by the patient. Care management for cancer patients is complex in its nature necessitating professionals to work across organisational boundaries and achieve the best outcomes for long term care management. When professionals do not do this effectively cancer survivors and their carers are often left to 'join up' the services themselves and there is greater reliance on voluntary organisations.

**Key words:** Interprofessional collaboration; Cancer care; Service users; Patients and carers; Voluntary sector

## Background

The incidence of 14.1 million new cases of cancer worldwide and 8.2 million deaths [1] necessitates the provision of high quality integrated and coordinated services. Following the diagnosis of cancer, the journey that patients and their families embark upon involves many different agencies, sectors and services working together to provide quality outcomes. The integrated nature of care can have different meanings in different contexts. In the UK the services involve health, social care, voluntary, private and independent sectors.

For many years the influence of joint inter-agency working to enhance health outcomes has been a focus of UK policy and legislation [2-4]. These acts and policies make assumptions regarding the workforce's capacity for understanding the nature of effective inter-agency working. In addition the inclusion of users' perspectives in developing understanding of the ways in which these agencies work together collaboratively to enhance the delivery of care is often missing. This study investigated the collaborative nature of professional working from the users' point of view within the context of one voluntary organisation. The study constructed narratives of journeys that cancer patients and their families (referred to as 'users' in this paper) experience and investigated the extent participants' perceived interagency collaboration during their journeys.

It is clear that many organisations delivering cancer care consider themselves to be effective in their collaborative working practices. However, there are concerns regarding the nature of this collaboration. Gagliardi et al. found only two out of twenty two studies in ten countries were explicitly collaborative. Most were practising 'parallel or consultative' models which were not truly integrative or coordinated [5]. The components of coordinated care have included different professionals and service providers working together [6]. The World Health Organisation (WHO) define a 'collaborate ready' health worker as capable of working in an interprofessional team focussing on their education and competence. They define collaborative practice as involving multiple health workers and are inclusive of anyone whose skills can be utilised [8]. Recently, Cortis and colleagues attempted to understand the nature of integrated care as represented in the literature [9]. They concluded that there were gaps in the studies that included all levels of the healthcare systems or service providers.

The problems are compounded as the impact of cancer is a growing concern with one in three people in the UK developing some form of cancer in their lifetime. Cancer is a disease which causes 14,000 deaths per annum in Scotland alone. Fifteen thousand cancer diagnoses are made each year in the authors' local area with breast; lung and colorectal being the top three cancers by incidence (NHS and ISD Scotland 2010). The European Cancer Patients' Bill of

Rights [9] recognised that every European citizen has the right to receive the most accurate information and to be proactively involved in his/her care. The extent to how well this is achieved has not been reported from users' perspectives. The aforementioned drivers from policy and legislation advocate that joint working across sectors share the burden of care and resources and that it is a logical approach to adopt to ensure cohesive working relationships that foster partnerships between patients and professionals. This concurs with other research contexts [10].

However, it is recognised that organisations involved with care delivery can become fixated with their own agendas and demonstrate 'silo' working practices that create boundaries to their practices. These boundaries act as barriers to interprofessional relationships and patients' quality of care can be compromised [6,8,11]. The authors of this paper concur that working interprofessionally across boundaries and with many agencies, strengthens organisations and facilitates the delivery of better health outcomes [6,12]. The inclusion of voluntary and independent sector organisations in research studies is important to ensure comprehensive exploration of the issues that impact on people with cancer.

This study focussed on investigating the impact of cancer on the lives of people attending a supportive voluntary organisation. The researchers were especially interested in the nature and scope of how patients perceived health and social care professionals' interaction and interagency working during their cancer journeys. Early writers [13] indicated that there are benefits to the service user of joint working between non-profit making organisations because of their shared common values, concerns for the community and their skill sets. It is commonly accepted that service users and carers value good relationships with professionals and that they perceive that the ways in which professionals coordinated care and services indicate good integration practices [14]. In cancer survivorship it is noted that effective communication within interprofessional relationships are fundamental to ensuring effective transitions in care [10]. These need to be further explored in the current move to integrated health and social care.

The project focussed on the nature and scope of concurrent service user engagement with services from different agencies. These agencies included the National Health Service (NHS); social services; local authority; voluntary; private and independent sectors. The voluntary organisation involved in this project was Cancer Link Aberdeen and the North East (CLAN), a charitable organisation providing services for patients, carers and families. CLAN works closely with other charities, NHS and Local Authorities when supporting clients. There were a number of established self-help groups within CLAN. Participants from these groups were invited to focus groups. The study was carried out at the premises of CLAN.

#### **The following research questions were identified:**

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

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?

## **Methods**

A qualitative study was designed to explore the narratives of patients and their relatives at various stages of the cancer journey. The 'talking wall' approach [15] was adapted for use with focus groups. The modification involved implementing a 'listening wall' and a 'three phase' approach. This enabled facilitators to actively listen to the narratives of the participants and enabled the participants to listen and respond to each other's narratives. The facilitators guided the focus groups using trigger questions and prompts encouraging discussion and participation.

There were three sequential phases to the focus group implementation. Firstly participants verbally outlined their personal story introducing themselves to the group. Secondly pictorial visualisations of participants' cancer journeys were invited. Thirdly specific questions were posed eliciting deeper insights into their narratives and discussion using 'listening wall' techniques to capture the journey. These techniques included using 'post it' notes written by participants and attached to flipcharts with specific headings depicting the cancer journey.

### **Phase 1**

During phase 1 participants introduced themselves to the group by stating their first name and a short description of their cancer experience to date. This allowed the participants to hear and empathise with their focus group peers and begin to deepen the narrative. The facilitators' role included prompting participants to begin telling their story and at other times to restrict participants from detailing the entire journey during this introductory phase.

### **Phase 2**

Phase 2 required the participants to reflect their cancer experiences visually to enabling a more discursive experience of the focus groups [16]. Some participants found this difficult and asked to be excluded from the visualisation. Those who did participate in this exercise produced some valuable pictorial data that reflected a range of aspects pertaining to their journeys.

The images and text were open to interpretation and were analysed using an adaptation of De Bono's six thinking hats [17] where colour coding was used to decipher the 'thinking' within the data. One team member conducted the analysis and circulated it to another team member for checking.

### Phase 3

Phase 3 of the focus groups was titled: 'my cancer journey'. Participants were guided to explore 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 at various stages of their cancer journey. These were defined as 'Before Diagnosis'; 'At Diagnosis'; 'Since Diagnosis'; 'Where are you now in your journey'; and 'Any other comments'. These were presented as headings on flipcharts placed around the room and participants were encouraged to write their responses to these trigger questions on 'post it' notes and place their views at any time during the discussions.

The focus groups were deliberately not audio recorded to enable free expressions, but transcribed with material from the listening walls using a framework analysis approach [18]. 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. Triangulating these three components enriched the data and led to deeper insights.

### Sampling and Recruitment

A convenience sampling approach was used to recruit participants and CLAN's existing support groups were targeted. These included cancer patients, cancer survivors,

carers and bereaved relatives. The 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. 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. Forty four people were recruited to the study and included cancer patients, survivors and family members.

### Ethics

The local NHS Ethics committee were consulted regarding this project and 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 University research ethics sub-committee. Due to the emotive nature of the topic, provision was made by CLAN to have additional support workers available during the focus group sessions to give counselling or support should this be needed and participants were informed of this service at the start.

### Findings

Numerical and demographic data are summarised in Table 1.

Project team members		
Total=7	Different professions	From two universities and CLAN
Focus Groups		
Total=4	53 responded	Males=11
	44 attended	Females=33
Timings 2 pm; 10 am; 12 pm; 10 am	Group 1=14 attendees	Facilitators=two different Research Team members per group
	Group 2=7 attendees	
	Group 3=14 attendees	
	Group 4=9 attendees	
Participants	Those who had lost family members =10	Cancers: breast, bowel, cervical, lung, lymphomas, prostate, rectal, skin
	Those who were cancer patients=34	

**Table 1:** Numerical and demographic data.

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 discussion too emotionally draining. Table 2 highlights the characteristics of the analysis for phase 2. The pictorial images were analysed according to the 'characteristic' as identified in Table 2.

The data from phase 3 were analysed using a framework analysis approach [18] deciphering major themes and sub-themes. The two major themes of 'the system' and 'the practitioners' emerged. These are highlighted in Table 3 and Table 4.

Colour	Characteristic	Related Comments	Explanation/Quotes
White	Facts	Dates/times/diagnosis/treatment regimes	Statements and/or diagrams
Yellow	Optimism and positive thoughts	Healthy and well/systems and services that worked well	“ Now much stronger as time goes on” “All treatment from diagnosis to death was excellent”
Black	Judgements and decisions	Diagnosis/surgery/types of cancers/ stages of cancer/operable or not/ inconclusive results/family history/GP, hospital, clinics/all clear/travel for treatment/self-fulfilling roles	“I was told that....”
			“My five daughters were tested....”
			Surgery performed
			“became a local coordinator”
Red	Feelings and emotions	Symptoms/happy or un happy/progression of disease/ lack of normality waiting times/ travelling and costs/ lack of competence/ misdiagnosis/waiting times/effect on family/ errors in appointment times	“Pain/tiredness/hair loss/ unwell/ side effects”
			“Shock/ depression/dying and bereavement”
			No support
			Lack of professional competence/ communication errors
Green	New concepts/creativity/new ideas	Resilience/perseverance/ purpose CLAN/volunteering/complementary therapies/ Maggie's Dundee & Edinburgh	Creating & joining support groups
			Undertaking volunteering roles
			“a reason to live”
			Breast Care Scotland/CLAN PINK group/ Mindfulness Roxburghe House/ CLAN Aberdeen & Stonehaven
Blue	Rationale/cause and effect	Diagnosis/family history/awareness/altruism/ reflection	“Delays in biopsy=speed”
			“Family history=cancer”
			“Nursing care lacking=lack of staff”
			“Cost of travel=impact on NHS”
			“Feel good=do something positive”
			“CLAN helpful=volunteer”
“On reflection=good health service”			

**Table 2:** De Bono analysis of focus group images.

Major Themes		
Stages of Journey	The System	The Practitioners
<b>Before diagnosis</b>	<p>‘GP acted very promptly and referred me to hospital without delay’</p> <p>‘Too long to wait for some test results. Long time to wait for treatments to be given.’</p>	<p>‘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’.</p> <p>‘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</p>

		paranoid'.
<b>At diagnosis</b>	'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.'	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.'
<b>Since Diagnosis</b>	'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".	'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'.
<b>Where are they now?</b>	'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'	'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'
<b>Other comments</b>	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.	At the end of my treatment I thanked my consultant and he said "It was 50:50, you did half of it." 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.

**Table 3:** Themes.

Stages of Journey	Sub-themes			
<b>Before diagnosis</b>	Characteristics of the disease	Impact on life and living		
<b>At diagnosis</b>			Shock	Other support services
<b>Since Diagnosis</b>				Other support services
<b>Where are they now?</b>		Impact on life and living		Other support services

**Table 4:** Sub-themes.

These major themes were identified throughout the stages of the cancer journeys. Participants' quotes from the focus groups are given as coded responses e.g. FG1=Focus Group 1 and R1=Response 1.

**Aspects that worked**

There were many positive comments about treatment and care received. These included the partnership working between patients and consultants. Consultants were

reported as inviting patients to participate in the options for treatment, leaving the decision to patients whilst guiding them towards optimal treatments. Exemplary care in the primary and secondary sectors was mentioned including care in the community and inpatient hospital experiences and outpatient radiotherapy services.

### 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.

Communication issues marred cancer journeys and there were unnecessary long periods of time spent waiting for their results "from all departments" (FG3R5). These were attributed to communication delays often due to failings in processes and the lack of use of modern technology i.e. doctors waiting for postal services instead of e mail. This led to a great deal of anxiety in an already difficult and painful journey.

There was a perception of a 'compartmentalisation' of services 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" (FG3R6). Social services staff resources were criticised, "dire shortage of carers to come in on a daily basis from social services" (FG2R5).

A few participants vocalised unresolved issues of loss and bereavement and this suggested that they were not coping as well as others. There was often support within the group for these expressions of anger and the participants listened and 'managed' each other's issues for the duration of the focus group. 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"* (FG4P2)

### Sub-Themes identified for the stages of the journey

Table 3 also highlights sub- themes that occurred at certain stages of the journey, identified in this study with the categories: 'Before diagnosis'; 'At Diagnosis'; 'Since Diagnosis' and 'Where are you now?'

#### Characteristics of the disease

The theme 'Characteristics of the disease' was only identified in the 'before diagnosis' stage of the journey.

Some key words were attributed to the theme 'characteristics of the disease' and 'treatment and care'. These are depicted as a wordle in Figure 1.



Figure 1: Key words for theme characteristics of disease- for all stages of cancer journey.

#### Impact on life and living

This theme was highlighted in two stages of the journey, namely: 'before diagnosis and where are you now?' Participants described their lives before diagnosis including the importance of 'work' and activity. However, the 'downward spiral, health loss and cancer spread' clearly had a major impact on their lives.

#### 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.

*'Was hungry, lost confused and cold'* (FG1P3); *'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'* (FG1P4); *'After test I was sent back to (the) room and when (the) door opened a whole host of people came in - very frightening'* (FG1P5)

#### 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 the 'clinical results' process improved. For example, a Dietetics follow-up was perceived as important especially after bowel surgery. The availability of support services literature within patient waiting areas was also recommended. Participants did not mention their awareness of any care planning arrangements such as survivorship care planning [19].

There were comments regarding the training of staff and they can be considered broadly into two areas. There

were perceptions that there was a lack of time available for staff training even though this was desirable and perceptions that staff did not acknowledge patient competence in understanding their own bodies. *"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"* (FG1P6). *"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. I hope I didn't need the oxygen because I didn't get any"* (FG2P7).

### **Value of participating in the study**

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 care. Whilst most enjoyed the group experience one comment related to preferring a 'one to one' experience to narrate their story.

### **Researcher reflections of focus groups**

The focus groups were not audio-recorded and 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' reflections and the content of the 'post-it notes'. The introductory session often took longer than the 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.

### **Group interaction**

The participants generally found the method 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 rather than verbalise. On one 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 a good flow of conversation and most groups demonstrated passionate and emotionally charged discussions. One participant reported that they 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 and identifying

coping strategies that they shared. 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.

### **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 described as '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 receiving 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 perceptions of the timeliness of information giving on the part of professionals and this was a positive experience. There were expressions of unresolved anger when cancers had been misdiagnosed or diagnosis had been delayed and a reporting of unfair service provision from one independent sector service.

### **Outcomes**

There was an affirmation of positivity with the focus groups 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 as support streams for the participants even though facilitators probed.

### **Discussion**

The discussion focuses on the main issues highlighted in this study, i.e. variability of the cancer care journeys; the partnerships between the voluntary organisation and health and social care sectors and the implications that these impose on other organisations. These are discussed in light of the findings and the existing literature on this subject.



### **Variability of the cancer care journey**

The findings of this study clearly highlighted that the care received by many of the users was variable. There were reports of extremely satisfied experiences of care and equally there were poor experiences. Many of the reasons for the two extremes of care provision were attributed to communication amongst the different members of the team looking after the cancer patient. Whilst there were examples of effective communication leading to efficient services and practitioners who demonstrated exemplary performance there were others for whom this was not the case and this hindered their cancer journey. This is at variance with the European Cancer Patients' Bill of Rights [9] which recognised three articles including the right of every European citizen to receive the most accurate information and to be proactively involved in his/her care. This disparity from the Bill of Rights has been identified in other areas concurring with the findings from this study. It does however concur with the lack of information sharing amongst professionals advocated by [10].

There were gaps in multi-service provision identified by the participants and most of these related to the NHS rather than different sectors. There is evidence that information sharing is greatly enhanced by integrated services [20] and this would be an area of focus for the participants who felt that their information was not being shared appropriately amongst health professionals. The findings concur with the views that users value good relationships with professionals [10,14]. The importance of having one key contact person throughout the cancer journey was identified by Walsh et al. [6]. This can strengthen the patient-professional relationship developing trust and communication. It can potentially alleviate the anxieties caused by the 'shock' experienced at diagnosis and the 'fear' that this stage of the journey can provoke [21].

This study found that when care was reported as exemplary this was due to the professionals meeting service users expectations for treatment and care and when care was found to be less than satisfactory 'human factors' played an important part. Service users noted that if professionals demonstrated their 'human' side and offered care and compassion then this outweighed the issues related to lack of information coordination and fragmentation of care. This concurs with other research findings [10].

The findings indicate that integration of services and collaborative practices do provide exemplary care as perceived by the service user. However, it would seem that collaborative models for cancer care whilst recommended are not standard. Disjointed care experiences were also noted by other authors [8,11] and that people could fall through the gaps created by the organisational barriers.

### **Inter-agency working: Voluntary health and social care sectors**

The aim of this study was to explore the nature and scope of concurrent engagement with services from different agencies by service users. These sectors included the

NHS, social services, local authority, voluntary, private and independent sectors. It is envisaged that agencies are working well together using joint working approaches and collaborative team work. Indeed the UK Government Health and Social Care Act (2012) [3] and the Public Bodies (Joint Working) (Scotland) Act (2014) [4] raises the expectation for an integrative model of health and social care services to be a reality for all. The participants in the focus groups did not highlight the breadth of discussion that might have been anticipated on the different agencies involved in their care. Rather the focus was on the NHS and its management systems with medical and nursing professional services receiving greater attention. There was minimal data on Social Services provision. This was unexpected and raises the question as to whether the CLAN participants were representative of wider society who regularly encounter local authority type 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. As well as this suggestion perhaps the study participants' lack of perception of other services is further evidence that service integration is not easily identified during the cancer journey. The findings here imply concurrence with previous findings [6,22] that there is still a general confusion and lack of understanding regarding the aims of integration. Where care was exemplary participants found that they could not fault it and they received more than they had expected. However, there were instances when care was very poor and these participants described greater feelings of anger and frustration that their expectations had not been met. To the researchers the surprising aspect of the data were these two extremes with no 'middle ground' where care delivery could be considered satisfactory or 'okay'. There was no apparent individualised plan of care communicated to these participants [19]. There is no further interpretation that can be given as to why this was the case other than the study was a 'snapshot' of people's experiences.

It is clear that joined up provision of care requires partnership working between different sectors and the importance of a greater role for the 'third' or voluntary and independent sectors is significant. The responses from participants were that cancer patients, carers and families' relied on CLAN and this forged significant relationships for their cancer journeys. Many spoke candidly of their need for CLAN's services especially when they were experiencing poorer service provision from health and social care. However, this aspect of a 'reliance' model of the voluntary and independent sectors potentially sealing the 'gaps' in health and social care provision, is very different to the collaborative and joint working approaches envisaged in the Public Bodies (Joint Working) (Scotland) Act (2014) [4] and others [23]. It is also perhaps a way of people in need seeking out the voluntary sector to assist with negotiating their way through complex systems of care delivery that transcend multiple organisational boundaries.

The web of health, social care, voluntary and independent organisations is a challenging area for someone with cancer, their families and carers to negotiate to discover



the appropriate resources and services that may or may not be available for enhancing their quality of life. These resources may be abundant in some areas and minimal in other areas. Families and carers may find it hard to locate appropriate resources. They rely on the knowledge and expertise of health and social care professionals, volunteers and other agencies to steer them to the appropriate resources in order that they maintain quality and dignity of life.

In the context of health and social care integration policies in the UK and Europe there is an assumption that health and social care professionals understand how to work collaboratively crossing organisational boundaries to signpost people to the best possible resources and that they understand how to do this well satisfying the high expectations of patients and their families. They are often seen as pivotal in guiding and directing families to resource and service provision. People with complex health needs need to be relieved of trying to 'join up' the services for themselves and provided with seamless resource and service provision. Care that is based on partnerships and collaboration with good communication and team working at its heart is the essence of the health and social care integration agenda.

This study is timely as recent reviews of third sector's roles in delivering social care have called for research to shape policy and practice. The findings support the need to highlight the implications for the third sector. Organisations will need to be aware of newer models of working such as 'coproduction'. Indeed one respondent when thanking a consultant for their care quoted him as suggesting that the patient was instrumental in directing their care pathway 'It was 50:50...you did half of it' (FG1R8). This indicated the 'co-productive' nature of the partnership between consultant and patient. Implementing co-production will require greater inputs from other professionals and charities [24].

### **Articulation, visualisation, and the listening wall**

Using the 'listening wall' approach (adapted from the 'talking wall' [15] provided valuable information on the service users' perspectives. The research team and others have previously used this approach and found it to be a valuable method for data extraction in focus groups [24-26]. The emergence of the term 'listening wall' was unique to this study and occurred as participants listened intently to others. The design of the three phases approach to implementation encouraged a deepening of conversations.

Participants' ability to 'draw' on visual images or text to portray their current perspectives on their journey related some insightful parts of their lives and their ability to deal with their cancer diagnosis and has been evidenced by others [16,23]. Many participants reported evidence of cathartic disclosure as the focus groups had given them the first opportunity to share in this way and that they felt better for it.

Analysing the visualisation data using De Bono's [17] six thinking hats enabled the extraction of the emotion expressed. On triangulating this with the phase three themes a

greater understanding of the users' perspectives was gained strengthening the validity and reliability of the study.

### **Limitations of the Study**

This was a small scale 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 may have had 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 cancer clients' experiences. Researcher bias in conducting the listening wall focus groups was minimised by ensuring that each focus group was facilitated by different pairs. When analysing the data the researchers allocated the initial data to one of the team who had not participated in the focus group facilitation providing a more detached perspective for theme development.

It could be argued that interprofessional collaboration and the emotions attached to 'good and bad' cancer care have been revealed in the same measure within the data. The participants directed their responses to the prompts given by the researchers and in this way determined their own narratives to the questions posed regarding what worked well and what did not work well for them during their journeys. This resulted in some deviation from the research questions posed. It could be argued that this study has not accurately identified the issues around multi-sector service provision from this client group. It has provided one voluntary sector client group with a voice and an input into the existing body of knowledge on users' perspectives on their cancer journeys.

Returning to the research questions the analysis of the data has attempted to extrapolate links to the facets of collaborative practice namely, the overlapping of professional responsibilities; the errors that can arise from ineffective team working; resource management and the strengths and weaknesses of management and leadership strategies for delivering quality care. It has identified the need for a larger study with user groups to address multi-sector service provision.

### **Conclusion**

This study sought to explore service users' experiences of receiving interprofessional collaborative care during their cancer journeys. The findings identified patients and service users describing a journey fraught with highs and lows, worries about health, concerns of the impact of cancer diagnosis for their families, fears for the future and realisation of personal mortality. The intensity and impact of personal involvement in this journey leaves little room for formal engagement with, and reflection on, the concept of interprofessional collaborative working. There is an

expectation that this will be in place and facilitate the passage through timely and appropriate interventions, referrals and communications. Only when this does not occur, and anxieties are raised does the need for interprofessional collaborative working become apparent to them. Where interprofessional collaboration and communication is effective this eased the cancer journey. The different yet interlocking interventions and support from statutory and voluntary agencies is a holistic approach that is appreciated by the patient. The education of tomorrow's workforce is an important consideration in developing professionals capable of delivering these services and working in this way. Adopting a framework founded on collaborative working practice and valuing care that is based on partnerships and co-production will drive forward a more effective health and social care integration agenda sensitive to the needs of users and the workforce.

## Recommendations

There are a number of recommendations from this study. Perceived inequalities of service provision across the different cancer treatments, need to be recognised by practitioners. For educators the need to promote multi-sector service provision, team working and communication processes within curricular developments for health and social care courses is paramount. Interprofessional educators are in the best position to ensure curricula across many different disciplines encapsulates health and social care integration and includes voluntary sector provision. For students aiming to appreciate service user understanding of their illnesses a placement experience or volunteering experience at an organisation such as CLAN would be valuable for their future professional development.

## Acknowledgement

The authors wish to acknowledge the significant support and encouragement received from CLAN's management and governing board to conduct this study.

The authors are indebted to the CLAN clients who participated in the focus groups and shared their stories so admirably.

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**Received date:** October 10, 2017; **Accepted date:** November 08, 2017; **Published date:** November 14, 2017

**Citation:** Joseph S, Barnard S, Macduff C, Moffat M, Walker P, Diack L (2017) Users' Perceptions of Interprofessional Collaborative Care during their Cancer Journeys'.. *J Health Sci Educ* 1(3): 122.

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