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Title:

Multi-professional perspectives on teenage and young adult oncology across Europe - An e-delphi survey

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Abbreviations:

TYA	**Teenage and Young Adult**
ENCCA	**European Network for Cancer in Children and Adolescents**
TYAC	**Teenage and Young Adults with Cancer**
SIOPE	**European Society for Paediatric Oncology**
EONS	**European Oncology Nurse Society**
MDTs	**Multi-Disciplinary Teams**

Abstract:

The aims of this paper are to describe the ongoing development of teenage and young adult cancer (TYA) services within the European Union, and develop consensus on key areas within the field. This survey used an e-Delphi design. An initial survey was distributed via email to professionals working in Europe. A snowball sampling technique was used to promote distribution. Consensus was sought over three rounds from October 2012 – April 2015. Consensus was defined as > 80% agreement ("agree" or "strongly agree"). Sixty professionals participated in round one, 106 in round two and 61 in round three. Twenty-six countries were represented across all rounds. Consensus was achieved for; the need for national policy guidance, the importance of patient choice, the validity of the International Charter of Rights for Young People and some aspects of multi-disciplinary working. There was 75% agreement on a single definition of the patient age range within TYA cancer care. European professionals with expertise in TYA cancer care reached consensus upon key elements of care for this group. The optimal TYA age-range remained an elusive topic on which to agree. The broad engagement and interest in TYA cancer across the EU through the ENCCA network was also demonstrated.

Introduction

Teenagers and young adults (TYA) remain a disadvantaged group in cancer care (Stark et al., 2015a; Lewis, 1996). The epidemiology of cancer types across a diverse age range positions them between existing children's and adult cancer services, with neither service meeting their unique needs (Stark and Lewis, 2013; Abrams, 2007; Fern et al., 2013a; Lewis, 1996; Morgan et al., 2010; Pearce, 2009; Thomas, 2006; Whelan, 2007; Woodgate, 2005; Stevens, 2006). Low patient satisfaction with care may have its' origins in inconsistent or underdeveloped existing national and local healthcare systems (Kelly et al., 2004; Fern et al., 2013b; Reynolds et al., 2005).

Cancer in TYA has not received equivalent structural investment or focus when compared to children's or adult cancers. In Europe, overall five-year survival rates are approximately 87%, resulting in 10,000 new long-term survivors each year in the European Union (EU) (Reulen et al., 2011). However survival for some cancers remains disappointing, when compared to similar younger, and slightly older patients (Thomas et al., 2010; Gondos et al., 2013), and survival rates vary considerably by nation and region (Gatta et al., 2009).

Specific TYA services exist in some countries, and key elements of services tailored to the needs of TYA have been suggested through initiatives such as The International Charter of Rights for Young People with Cancer (Rajani et al., 2011), but the evidence to support specific service change remains underdeveloped. Many challenges exist, including a range of policies and service configurations between European countries, and between departments within individual hospitals. For example, different age ranges are considered as TYA in cancer between and within health care systems. A holistic TYA cancer service which meets specific critical clinical, developmental, psychological and social needs of its users is required, but agreement around its core elements and definition is needed. Two initiatives are driving forward change.

First, an existing international initiative which seeks to represent the views of the TYA cancer population was launched in 2010, through the collaboration between five worldwide charities, it aims to raise awareness of the needs of TYAs throughout the world, and improve their access to effective, holistic care, from diagnosis to survivorship, and despite geographical location. Second, The European Network for Cancer in Children and

Adolescents ('ENCCA') is a network of research institutes and clinical organisations recognised for their excellence in paediatric oncology, developed within the European Seventh Framework Programme for Research (FP7, 2011– 2014). This network aims to integrate all stakeholders involved in childhood and adolescent cancer, to raise standards of care across Europe. Among the 18 projects and activities, work package 17 was 'Improving Outcomes for Teenagers and Young Adults with Cancer' (Stark et al., 2015a). As part of this initiative, we aimed to understand and scope the ongoing development of teenage and young adult cancer (TYA) services within the European Union, and develop consensus on key areas where possible, making a significant contribution towards the European Cancer Plan for children and adolescents, outlined by SIOPE (Vassal et al., 2016).

Materials and methods

Primary Aims:

1. To survey professionals to understand the ongoing development of TYA services within the EU, and develop consensus on key areas within the field now and for the future.
2. To benchmark the development of services, as a baseline and to map change over time.

Secondary Aim:

1. To share best practice, engage and interest stakeholders, contributing towards the delivery of an equitable service to TYAs across the EU.

Study design

We conducted an e-Delphi survey, to facilitate structuring a discussion of diverse views using a multi-stage process (Jones et al., 2008). The Delphi method was developed by The Rand Corporation in the 1950s in an attempt to minimise interpersonal interactions during decision-making (Dalkey and Helmer, 1963). The technique is useful where the best available information is expert opinion and now primarily used to reach a consensus in the absence of a gold standard scientific answer, to gather opinion and initiate debate (Goodman, 1987; Keeney et al., 2006). Although used in a variety of studies, it has also been used to develop and refine clinical research priorities (Mcilfatrick and Keeney, 2003; Soanes et al., 2000). Information is collected individually from a panel of experts, responses are unknown to other panel members, and participation is kept confidential (Biondi PD, 2008). Responses are analysed, summarised and returned to panel members for further consideration and response in a series of data collection 'Rounds' (Keeney et al., 2006). Rounds are repeated until consensus of opinion, or a point of diminishing returns, is reached (Keeney et al., 2006).

Within the context of health care the quasi-anonymity of the Delphi technique is an advantage (Hasson et al., 2000).

Sample

The Delphi technique does not use a random sample representative of the target population, but seeks people with expertise. We defined 'expert' as any healthcare professional working within TYA cancer care, practice or research. Multiple routes were used for recruitment:

1. Purposive sampling of TYA oncology practitioners known to the research team;
2. Snowball sampling via existing professional groups (TYAC, SIOPE and ENCCA): working like a chain referral ensuring recruitment of professionals credited by other participants.

Procedure

Three rounds of data collection were undertaken between October 2012 and April 2015 (Figure 1). Repeat rounds were conducted until a rich description of views were gained.

Ethics

The study was approved by London South Bank University Ethics Committee (UREC number 1249). Participant data was held on secure servers hosted by the University of Leeds and personally identifiable data was not shared outside of the research team.

Questionnaire Development

Each questionnaire was developed by consensus in the research team, a group of experienced TYA professionals, working within ENCCA. The initial content was generated from areas of continuing uncertainty or inconsistency within the TYA community, based upon literature, congresses and discussions within the ENCCA network. Our topic areas were;

- definitions
- services
- research
- service-user involvement
- professional relationships
- future developments

Open questions were used throughout to promote explanation of answers and responses, extending the range of response options suggested.

The survey was piloted with three known TYA healthcare professionals in Europe before being distributed. The questionnaire requested professional role, whether specialist in children's, TYA or adult oncology and the length of time they had worked in this role. Some terms were edited throughout for clarity, given the diverse multilingual sample (Table 1).

Based upon the first round responses, the round 2 questionnaire was piloted with four TYA professionals locally prior to dissemination. Second round questions were repeated to a wider distribution to improve detail, including through ENCCA, SIOPE, EONS and TYAC. New questions were added:

- Agreement with the International Charter of Rights for TYA (Rajani et al., 2011)
- Open questions following closed questions to understand responses. For example, participants were asked if they would value national guidance, to which they could answer "yes" or "no". They were then asked to provide a reason for their answer, followed by open questions about how such guidance might be overcome barriers to implementation.

Round three was to seek consensus, sent to self-selected participants. Participants were emailed a link to the questionnaire and the overall round two results, highlighting areas where consensus had been achieved, where consensus was close, while retaining detailed questions to obtain a thorough understanding of views. In round three, multi-disciplinary team (MDTs) membership was examined further, by ranking the relative importance of a list of TYA professional roles identified in round two.

Analysis

For each survey round, questions were analysed for consensus and consideration of the content for any further round. Percentages were calculated for each statement for each professional group and reported as the total percentage response. Consensus was defined at the outset as > 80% agreement ("agree" or "strongly agree") on any statement.

Quantitative data were described by reporting frequencies of individual responses, comparing nations and regions. Text responses were analysed using a thematic analytical approach

(Braun and Clarke, 2006); scrutinised and categorised into emerging themes where commonalities were found.

Results

Round One

Sixty questionnaires were completed and analysed in round one. Professionals from 21 different countries were represented: either doctors (n=39; 65%) or nurses (n=12; 20%), with the remainder unknown (n=3; 5.0%).

Participants from nine countries reported they had no defined ‘age’ for TYA. Participants reported a range of ages encompassing 0 years to 39 years. The most frequently reported age-range was 15-19, described by participants from three countries. Several participants commented that age-range definitions varied by disease type. Participants from twelve countries stated TYA were not recognised as a distinct group for service delivery. Participants from nine countries reported having dedicated TYA units, but specific clinical teams were only reported from participants in seven countries and only four countries were reported to have funded TYA services. Participants from ten countries reported formal TYA care pathways. At the individual level when asked where TYAs were cared for, the most common response was adult and children’s services (n=15).

Specific TYA research groups were reported by 47% of respondents, and a range of research interests including; epidemiological cancer registration (n=82%), recording clinical trial entry (n=57%) and patient experience (n=90%). Involvement of patients in research and services was indicated by 56% of the sample. Participants were asked an open question about their priority research areas for the future of TYA, the five most common fields were: communication, survivorship self-management, end of life care, fertility preservation and transition from children's to adult services. Seventy-eight percent indicated they would be interested in joining an international professional research group.

Round Two

One-hundred and six questionnaires were completed from 22 countries. Figure 2 shows the location of unique participants recruited across rounds 1 and 2. The majority were doctors (n=68; 64%) and nurses (n=17; 16%), with other roles including physio/occupational therapist (n=5; 4.7%), psychologist (n=4:3; 8%), epidemiologist (n=4:3; 8%) and other (n=8; 7.5%).

Following up from round 1, 68% of respondents thought that an agreed TYA age range in Europe would be a useful aim. The mean optimal TYA age-range selected was 13-27, justified by the specific age-appropriate needs. Free-text responses highlighted a general policy but flexibility to accommodate circumstances:

> *"For policy and comparison of services, definition should be standardised and based on chronological age. This should be applied with some degree of flexibility to individuals at the discretion of MDT".*

Over 90% of participants (a clear consensus) would value national policy guidance about TYA services, to improve consistency in TYA care including: referrals, research, networking and access to resources. Participants thought there should be a multi-disciplinary approach to developing national policy guidance, including patients. The most commonly cited barrier to developing national guidance was perceived to be professional:

> *"getting adult physicians on board, convincing them that such a service is not a threat but an opportunity*".

Only 55% of participants said that they were aware of the International Charter of Rights for Teenagers with Cancer before completing the survey. The individual components of the charter were agreed upon by over 95% of the participants. The charter resonated with their professional experience. Four people commented the charter was applicable to all cancer patients (young or old), as well as to other illnesses.

Over half, 53% of participants indicated that TYA patients were given a choice about where their service provided care, such as between a regional specialist and a local general hospital, or between specialised TYA care and paediatric/adult care respectively. It was reported these choices were not available for patients under 16 years. Some questioned how real these choices were or how often young people were made aware of them.

Specific teams of professionals dedicated to the care of TYA were reported by 58.8% of respondents. The most often named MDT roles were; oncologist (n=95), haematologist (n=48), social worker (n=39), psychologist (n=47), nurse (n=37), education worker (n=21), surgeon (n=19), nurse specialist (n=17), radiologist/radiotherapy expert (n=17), activity coordinator/youth worker (n=16), physiotherapist (n=15) and dietician (n=14).

Approximately, 35% of participants reported their country formally asked patients about the quality of their care. This was primarily via a survey, although some other face-to-face methods were described. Forty-nine percent included patients in the design/planning of services and 23% included patients in the design of TYA research.

Formal working relationships were more common between TYA and paediatrics (61%) than between TYA and adult care (39%). Only 29 out of 106 participants reported that paediatric and adult cancer care worked together formally. Informal working was defined as ad-hoc, infrequent and needs-driven contact:

> *"There are a lot of differences between services and inconsistencies across service providers which make formal working in some areas very difficult. Much is achieved by good will and directly communicating with members of the team rather than formal working arrangements."*

Participants were asked to identify their top five research priorities for TYA from a list generated from the open question in round 1. They indicated biological research their top priority (n=35), along with timely diagnosis (n=30) and clinical trials (n=29) (Table 2). This data is useful for setting overall TYA research priorities; however there was some variation in priorities between regions of Europe. For example, biological research appeared most often in the top-five research priorities of participants, but was only seen as very important by 14% of participants from Eastern Europe.

Round Three

Sixty-one questionnaires were completed in round three from professionals representing 15 countries.

An age-range for TYA was proposed and agreement approached consensus- 75% of participants agreed with an age-range for TYA of 13-30 with flexibility at either end to accommodate individual circumstances and local variations. There was agreement that this age-range covered the physical, biological and psychosocial needs particular to TYA. Those who disagreed felt that age-range should be distinct for different TYA cancers.

Over 98% of participants agreed that TYAs should have a choice in their place of care. This was most frequently suggested for those between 16-19 years, to choose between children's, TYA or adult care. These responses were from countries with established TYA services and from countries in earlier stages of service development. Participants acknowledged that the choice needs to be "*real" and "informed"*, acknowledging this is difficult for patients early during diagnosis and treatment.

The data from round two was used to propose a list of professionals who should attend three distinct MDT meetings: psychosocial; diagnostic/treatment; and long term follow up (Table 3). Psychologists, social workers, education workers and activity co-ordinators were seen as essential members of a psychosocial MDT, whereas nurse specialists, nurses, oncologists, haematologists, physiotherapists and dieticians were seen as less essential, but still desirable. The involvement of surgeons and radiologists was deemed either not needed, or dependent on their involvement with the particular cases under discussion. The suggested diagnostic/treatment MDT was formed of a core team of oncologists, haematologists, radiologists/radiotherapists, surgeons, nurse specialists and nurses, with the other roles needed in specific circumstances. The make-up of the long-term follow up MDT was slightly less clear. Oncologists, haematologists, nurse specialists, psychologists and social workers were all thought to be essential by over 50% of the participants. Surgeons were thought to be essential by less than 10% of the participants.

Participants were asked about the extent to which TYAs themselves were involved in research. Overall, the most common TYA involvement was through patient testimonials (78.7%) and the dissemination of research findings (54.1%). There was far less TYA involvement in priority setting (39.3%), research design (34.4%), research management (19.7%), carrying out research (26.2%) and analysis (21.3%). However, there was variation across countries and Italy was the only country where all participants indicated that patients were involved in every aspect of research. Belgium and Czech Republic were the only countries where no participants indicated patient involvement in any aspect of research outside of dissemination.

Discussion

Our primary aim was to understand and scope the ongoing development of TYA services within the European Union, and develop consensus on key areas where feasible. Consensus was achieved on some aspects such as, the need for national policy guidance and the importance of patient choice. An agreed definition of age did not reach our '*a* priori' consensus threshold and neither did the composition of the MDT. Despite these remaining areas of divergence, this mapping exercise does provide a baseline, to report change at a later time, linking where possible change to policy and research.

As reported recently from the ENCCA network progress towards providing optimal care to TYA is happening, but at different rates across Europe (Stark et al., 2015b). Central to progress is of course national policy, and the building of robust networks and coalitions of engaged stakeholders (Barr et al., 2016). There was a clear consensus in round 2 of the need for national policy, developed by members of the multi-professional team, to include also patient groups. What is an added complication in TYA cancer care is the need to consider the breath of relevant policy areas, that includes health policy that influences services for these patients that relate to children and young people in general, as well as cancer-specific policy initiatives, with national strategy on health and social care, education and families providing the broader policy context within which young people's cancer services operate within most European countries (Hooker et al., 2009). This means that collaborations may be many, negotiations extensive, and in some cases systems and care processes may need to be challenged by a collective and more powerful voice that might affect change rather than lone voices in individual countries. The International Charter of Rights for Teenagers with Cancer we might agree is a good place to start to advocate for TYA's with cancer (Barr et al., 2016), but even in our expert panel only 55% knew of the charter before our survey. This would indicate there is some way to go if this is to help in raising standards of care across Europe and making available to TYA choice in place of care.

A shared research agenda could facilitate consolidating advances, and reducing current disparities in treatment and care. Partnerships, national and international research could afford benefit beyond a single institution. Setting research priorities is known to be a good place to start, and so our survey asked our expert panel to list their top five priorities (Table 2). Interestingly an e-survey of TYA undertaken by members of the ENCCA network at the same time as this Delphi survey also asked about research topics: the most frequently endorsed area for research was “monitoring after treatment”, which was followed by “communication between professionals and young people”, “research about cancer”, “fertility preservation” and “preparing to go back to work/school” (Jones et al., in press). Topics suggested were remarkably similar between the two surveys, using different terms as one might expect between a professional and young person population, and comparison of the two groups identifies a shared priority list that places fertility preservation in the top six, research about cancer in the top three, and timely diagnosis in the top seven. For both groups communication, clinical trial entry, long-term follow up care, education and vocation also featured, but only the young people mentioned the effect on family and friends, and financial worries: further evidence of the need to include both ‘professional’ and ‘patient’ expert views in research setting exercises to ensure a complete and comprehensive list is obtained (Chalmers et al., 2013; Galán et al., 2016).

The age conundrum within the definition of TYA we recognised at the outset would present a challenge to our expert panel. Variation exists, both between and within countries, and there have been unremitting calls for flexibility (Barr et al., 2016; Smith et al., 2016; Barr et al., 2011), rather than a hard agreement based on a chronological definition. Consistent with published work our panel were less concerned about the lower age limit, although even here flexibility was requested. The acceptance of an upper age limit up to and beyond 30 was accepted, although not by all panel members. We might continue to diverge on agreed limits, while stressing the need not to have restrictive age cut-offs for practice (Stark et al., 2015b), being mindful that different health care systems use different definitions because their existing systems of care differ and legal jurisdictions vary (Wilhelm et al., 2014), accepting then that it can be difficult to interpret age-specific research findings without consistent usage of clinically relevant and theory-driven conceptual age boundaries (Docherty et al., 2015).

Less controversial we thought was the composition of the multi-professional team, but this was the second area where there remained some divergence across our expert panel. We might have anticipated this, as some roles may not to exist across some European countries (such as activity co-ordinators) and accepting that it would be unreasonable for all institutions, large and small, to have access to the same personnel. From a list of participant generated roles in round 2, we presented our expert panel with a combined list in round 3 and asked them to place each role within three discrete descriptions of multi-disciplinary teams. The category “depends” in the third round was essential in highlighting the importance of a specific diagnosis indicating extent of the involvement of professionals with each patient. Similar to age, this variation in personnel might continue, and going forward it might be useful to consider a continuum of care for personnel as proposed by (Zebrack et al., 2010), or a description of competencies as opposed to role definitions as described by (Taylor et al., 2016).

The main strengths of our work are the inclusion up to round 3 of at least 15 countries in our expert panel, enabling us to offer a commentary on a point in time on the TYA network of care across Europe, highlighting clear areas of consensus as well as areas of divergence that we can continue to map in the coming years. However, some limitations also need to be recognised. First, our expert panel was determined through our approach to sampling. Using professional networks and our snowball sampling means we relied on ‘others’ to disseminate our survey. In future work, targeting individuals might help in maintaining response rates through to round 3. Second, the collection of minimal ‘demographics’, limited our opportunity to examine variability in responses, for example, panel members from established TYA services and those from new services might well have been expressing different views, and these would have been interesting to examine further. Third, our survey was presented in the English language which may have prevented some individuals or professional groups from participating

Conclusion

This e-Delphi study was the first of its kind to attempt to gather consensus about aspects of TYA care from TYA oncology professionals across Europe. Consensus was achieved in relation to; the need for national guidance, the importance of patient choice in their place of care, the validity of the International Charter of Rights for Young People, certain aspects of MDT working and a near consensus on the definition of the TYA age-range.

The survey has also demonstrated broad engagement and interest in TYA cancer care across the EU. Over 100 professionals from 26 different European countries participated in this survey and reflected on the TYA specific issues it addressed. The ENCCA network has grown substantially as a result this survey and the network continues to gather new professionals with an interest in TYA oncology.

Working to consolidate the consensus on key aspects of TYA cancer care and understand how to implement effective systems, produce high-quality and high-priority research and innovate to engage the host of individuals involved in this unique area of cancer practice are our ongoing tasks. The goal of reducing the ‘dip’ in survival, quality of survival and cancer experience is within our collective reach.

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Figure 1 Delphi responses

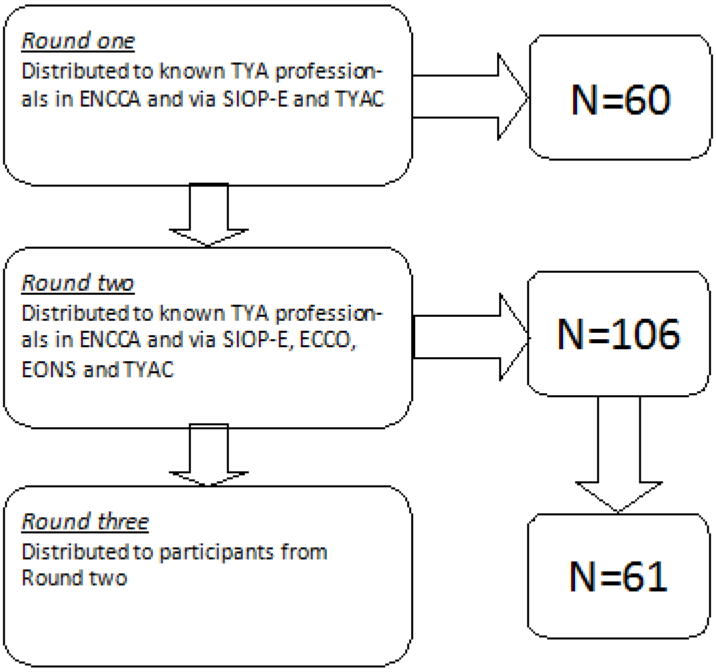

Table 1 Changes following pilot of questionnaire

A recommendation for a TYA age-range for participants to agree or disagree with, which was based on the data gathered in Round two
A reworded question about TYA services
A question about patient choice regarding services
A list of suggestions for TYA professionals who would comprise three different MDTs (psycho-social, diagnostic/treatment or long term follow up). The list of professionals was based on the suggestions of participants in Round two. The addition of the three separate MDTs arose from an ENCCA steering group meeting where the results of Round two were discussed and the group reflected that these three different MDT meetings involving different professional occur in many of their Centres;
A reworded question about professional team working
More detailed questions about TYA professional education, which were based on the data gathered in Round two and a recent professional symposium held by ENCCA
More detailed questions about how patients are involved in research

Figure 2 – Unique participants from rounds one and two

Table 2 Research priorities

The frequencies in the second column represent how many times a factor appeared in a participants' top five.

Table 2							
Factor	Frequency in top 5	Percentage of respondents indicating "very important" per region					
		UK	West	North	East	South	Central
Biological research	35	77%	65%	83%	14%	60%	84%
Timely diagnosis	30	80%	61%	86%	57%	73%	47%
Clinical trials	29	80%	48%	86%	50%	60%	63%
Long term follow up	26	69%	74%	72%	57%	93%	79%
Psychological wellbeing	25	83%	70%	100%	71%	87%	68%
Fertility	24	71%	78%	57%	29%	87%	63%
Improve patient experience and QoL	21	88%	61%	100%	71%	93%	67%
Survivorship and self-management	20	74%	70%	100%	43%	80%	63%
Education/vocation	19	71%	73%	86%	29%	80%	63%
Transition	19	72%	83%	71%	29%	80%	79%
Communication between TYA and professionals	15	71%	77%	100%	43%	87%	74%
Monitoring post-treatment	14	66%	65%	71%	57%	87%	74%
End of life	12	83%	82%	86%	50%	87%	63%
Prevention and screening	12	57%	32%	43%	29%	67%	58%

Table 3 Membership of the multi-disciplinary team

Role	**Essential%**	**Desirable%**	**Not needed%**	**Depends%**
Psychosocial MDT				
Psychologist	98.4	1.6	0	0
Social worker	96.7	3.3	0	0
Education worker	72.1	24.6	0	3.3
Activity co-ordinator	72.1	19.7	0	8.2
Nurse specialist	59	21.3	13.1	6.6
Nurse	54.1	34.4	6.6	4.9
Oncologist	41	42.6	4.9	11.5
Haematologist	37.7	39.3	8.2	14.8
Physiotherapist	31.1	31.1	18	19.7
Dietician	29.5	42.6	9.8	18
Surgeon	6.6	14.8	54.1	24.6
Radiologist/radiotherapist	6.6	21.3	49.2	23
Diagnostic/Treatment MDT				
Oncologist	96.7	0	0	9.8
Haematologist	95.1	0	0	4.9
Radiologist/radiotherapist	75.4	9.8	1.6	13.1
Surgeon	68.9	11.5	1.6	18
Nurse specialist	65.6	21.3	1.6	11.5
Nurse	55.7	31.1	4.9	8.2
Dietician	23	37.7	23	16.4
Social worker	19.7	39.3	27.9	13.1
Activity co-ordinator	19.7	29.5	32.8	18
Physiotherapist	18	31.1	19.7	31.1
Psychologist	14.8	49.2	23	13.1
Education worker	13.1	31.1	36.1	19.7
Long Term Follow up MDT				
Oncologist	75.4	14.8	0	9.8
Haematologist	63.9	18	0	18
Nurse specialist	55.7	21.3	4.9	18
Psychologist	54.1	39.3	0	6.6
Social worker	50.8	39.3	0	9.8
Education worker	39.3	36.1	4.9	19.7

Nurse	31.1	39.3	13.1	16.4
Activity co-ordinator	29.5	42.6	9.8	18
Physiotherapist	23	39.3	6.6	31.1
Radiologist/radiotherapist	16.4	29.5	24.6	29.5
Dietician	13.1	42.6	9.8	34.4
Surgeon	6.6	18	41	34.4