

An evaluation of outpatient services for teenagers and young adults with cancer in Leeds Teaching Hospital Trust, paying particular attention to peer support, specialist nurse input and physical environment.

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Introduction

Although cancers affecting Teenagers and young adults (TYA) account for less than 1% of cancer incidence in the UK, it is the leading cause of non-accidental death in this age group and thus is a significant health concern (Teenage Cancer Trust 2010). TYA are defined by being neither child nor adult (approximately 13-24 years) and similarly rarer cancers which commonly affect TYA often reflect neither paediatric nor adult morphology. Through the help of the charity Teenage Cancer Trust (TCT), TYA voiced opinions of being 'lost in a no-man's land' between paediatric and adult hospital services, neither fully equipped to meet their holistic care needs. TYA-specific services evolved to meet this need through age-appropriate environments and care around peers, delivered by holistic TYA cancer experts. As care standards are increasingly assessed with patient-reported outcomes measures (PROMs), it is imperative services ensure they are meeting both clinical 'biomedical' patient needs, but also meeting patient's expectations of care. In order to inform areas of improvement across Leeds Teaching Hospital Trust (LTHT), this service evaluation used questionnaires to measure patient satisfaction with age-appropriate TYA outpatient services, with particular focus upon physical environment, peer support and clinical nurse specialist (CNSs) input.

Background

Although TYA are acknowledged as a distinct patient group with specific health needs since the Platt report (1959), the Calman Hine report (1995) was the first national paper to acknowledge specific needs in cancer care. Factors including late diagnosis, lack of TYA specific protocols in clinical trials and limited research into TYA cancer pathophysiology were attributed to poorer TYA five-year survival compared with adults and children with same cancers (O'Hara et al 2012). Similarly in transition to adulthood, TYA experience significant psychosocial development which, DOH has stated, must be acknowledged when designing services to prevent future detriment to health and wellbeing. In order to address these issues, The TCT is a charity which has evolved to advocate the needs and rights of teenagers with cancer on a national and international level in political affairs. In consultation with TYA (Conference findings) in 2005, NICE guidelines were published that proposed that Age-appropriate care should be provided in regional TCT Primary treatment centres (PTC), to concentrate expertise in TYA cancer care, with the aim of improving survival and patient satisfaction.

What Services are Provided in LTHT?

Although there is a paucity of literature defining features of age-appropriate *outpatient* clinics, it proposes that optimal TYA care should be coordinated via a regional TYA-designed TCT unit, staffed by TYA cancer experts (especially clinical nurse specialists) with access to age-appropriate facilities and opportunity to meet others their own age. Services at LTHT, outpatient clinics attended by TYA are

conducted at one of 3 sites: Leeds General Infirmary (LGI) Paediatric Day Case, St. James (SJUH) TYA specific outpatient clinic (dealing with 'solid' tumours) or Haematology outpatient clinic at SJUH. Of these, only the LGI paediatric unit had a room specifically designed for TYA (with Playstation® and computer) to wait with peers before clinic. However the SJUH TYA outpatient clinic, exclusively for TYA patients, also provides refreshments and access to age-appropriate, expert staff e.g. activity coordinator, CNSs and psychologists whilst waiting around peers. Although patients attending haematology outpatient department wait in a generic outpatient clinic, generally populated by adult and elderly patients, they can request the presence of the TYA clinical nurse specialists whilst awaiting appointments.



Photograph 1 of LGI waiting area for TYA (above)



Photograph 2 of generic haematology waiting area (above)



Photograph 3 showing magazines within haematology clinic (above)



Photograph 4 showing SJUH TYA clinic area, used by only TYA patients during this particular clinic, with TYA expert staff and refreshments (above)

Why service evaluation?

The government's 'Liberating the NHS' white paper (DOH 2010) claims the best way to improve NHS care quality is by moving away from process-focussed targets towards measuring 'health outcomes'. The Department of Health defines these 'Health outcomes' in the document '2013/2014 NHS outcomes framework', one of which aims to 'improve patient experience of outpatient care' through service evaluation. More specifically the government's national cancer peer review program (National Cancer Action Team 2011) advocates questionnaire use to ensure services implemented under NICE 2005 guidelines meet patient expectations. TYA 'Blueprint for care' (Smith et al 2012) and a summary of patient feedback on health outcome measures (TCT 2012) claim that patient-reported outcome measures are the best way to evaluate satisfaction with TYA services and maintain communication between service providers and users.

Aim

The aim was to evaluate outpatient services for TYA cancer patients across the LTHT by identifying levels of patient satisfaction, to inform potential service improvements.

Objectives:

To identify satisfaction levels with current LTHT TYA cancer outpatient services with particular attention to satisfaction with TYA-specific factors:

1. Physical environment

2. Clinical nurse specialist (CNS) input
3. Peer support.

And satisfaction with the 'generic outpatient' aspects of service:

4. An 'overall' satisfaction score of TYA cancer patients in the three different TYA outpatient sites across LTHT will be calculated to determine whether location of services affects the satisfaction.

Methods

Ethical approval consideration

Service evaluations do not require official NHS research ethical approval since aims are to measure and judge existing care standards, not generate new knowledge (National Patient Safety Agency 2009). Permission was granted from all doctors and CNSs who worked in clinics evaluated. Ethical considerations such as patients' informed consent and confidentiality were followed.

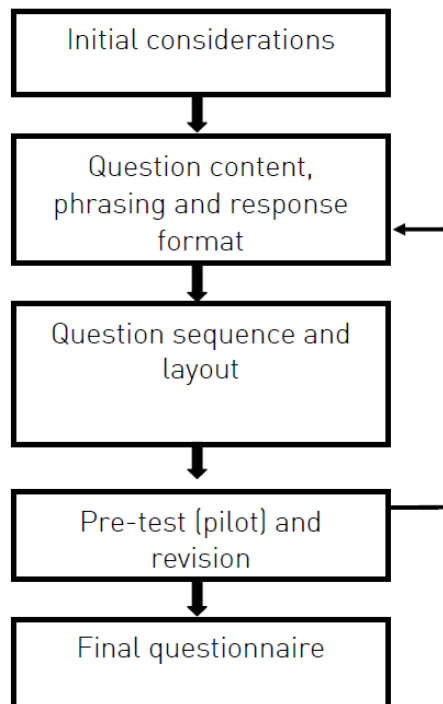
Initial project planning considerations

Meetings were arranged with key clinicians and administrative staff involved in the running of LTHT TYA outpatient services- invaluable to gain understanding of service organisation, delivery and aspirations. Regular staff feedback was sought via meetings and email, due to their valuable experience and advice in conducting service evaluations with this patient group.

Attending clinics was useful to see different clinic environments; gain some understanding of patients' outpatient journeys; experience clinic atmospheres and observe the clinic processes from arrival, waiting, through consultations to post-clinic arrangements.

Questionnaire development

Questionnaire development was based on flow diagram 1.



Flow diagram 1 demonstrating the key stages in the project's questionnaire production (taken from Kirklees Council n.d.)

Questionnaire content

Familiarisation with questionnaire writing guidance and research into past outpatient satisfaction questionnaires was undertaken. A peer-reviewed patient reported outcome measure was identified, which had been designed by LTHT TYA oncology staff and was recommended for use in evaluation of TYA outpatient services (Phillips, Absolom, Stark & Glaser 2012).

This was modified to incorporate certain domains which were identified as pertinent to TYA satisfaction with cancer services in our literature reviews. These domains also focused the questionnaire to address our objectives relating to evaluation of physical environment, CNS input and peer support in particular; areas which were thought to be potentially variable across the three LTHT sites.

Royal College of Physicians' (2004) guidance on providing user-friendly outpatient services also informed further questions relating to the general outpatient experience, as opposed to specifically TYA-important issues. The chronological structure of the guidance of before, during and after clinic informed question sequence as it was considered a logical structure for respondents.

Questionnaires had introductory information explaining its purpose for informing service improvement; reassuring confidentiality and that care would not be affected by responses. It also asked those who had already completed the questionnaire not to repeat it, and for completed questionnaires to be returned to receptionists.

The first questionnaire section asked demographic information, before asking questions regarding satisfaction with various aspects of outpatient experience. There was a comments section where it was hoped some qualitative data or improvements suggestions would be obtained.

Questionnaire format

A four-point likert scale from strongly agree to strongly disagree was used, with removal of a neutral response to encourage TYA to commit to satisfied or not. It could be argued this encourages expression of opinions which may not necessarily be as strong as answers indicate. Both positive and negative statements were asked to be responded to. This is considered useful in minimising “respondent acquiescence”, however some suggest negative satisfaction statements can cause falsely enhanced satisfaction responses (Wilson et al. 2006).

Feedback and Piloting

Questionnaire feedback and permission from TYA oncology staff was agree. Questionnaires were piloted with five people in SJUH TYA clinic, since testing with small numbers of the population group of interest enhances questionnaire validity (Allen 2012; Watson & Coombes 2009). This ensured it was an acceptable length, comprehensible and clearly presented. No changes were required therefore this was the only pilot and this data was retained for analysis.

The final questionnaire is in appendix A.

Participants and sample size

Participant inclusion criteria were 1) patients between 16-24 years old, 2) receiving oncology outpatient care, 3) in either LGI paediatric outpatients, SJUH TYA clinic or haematology adult clinic settings. This age bracket was set as the cancer reform strategy (DOH 2007) states TYA of between 16-24years should be referred to primary treatment centres like Leeds, for diagnosis and specialised care planning. This range also allowed comparison of patient satisfaction across all three sites whilst limiting the large, potential age range of 13-25years. This wide spread of maturity and service expectations would likely have complicated analysis beyond the novice researchers' capabilities. Both males and females could take part.

57 patients were recruited, 26 from SJUH TYA cancer clinic; 6 attending SJUH haematology adult outpatient clinics and 25 attending LGI paediatric oncology outpatient department, from January until mid-February 2013 over a 7 week period. Convenience sampling was used due to time constraints necessitating recruitment of as many respondents as possible, and also limited potential participant numbers using haematology outpatient services.

Suitable patients were recruited on arrival to clinics. Most SJUH TYA clinic patients were within age range and at LGI suitable teenagers were fairly easily identifiable on arrival to the paediatric department, there're receptionists helped with identification at

these sites when students were unable to be at clinic due to placements. Haematology clinic recruitment was more problematic as there were extremely low numbers of potential participants within age range. Therefore upcoming clinic lists were printed, the few suitable patients were highlighted and these lists were given to receptionists before clinics. This way burden of participant identification was not carried by receptionists.

Data handling

All questionnaires were numbered and data input into a spreadsheet. The data matrix followed the question order, and data entry was checked by both researchers (Allen 2012). Missing data was highlighted with no figure entered, so Excel calculations did not count this as anything but incomplete data (Allen 2012).

As questions were both positive and negative, this was accounted for during data inputting. Agreement with positive statements received high scores (e.g. strongly agree- 4, strongly disagree- 1), whereas agreement with negative statements received low scores (e.g. strongly agree- 1, strongly disagree- 4). Therefore, higher scores meant more positive experiences and higher satisfaction.

For example, the following responses would both be awarded scores of 4:

During clinic, the teenage and young adult (TYA) clinical nurse specialists:				
	Strongly agree	Agree	Disagree	Strongly Disagree
Are easy to approach if I want to talk.	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Get annoyed if I ask too many questions.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>

Data analysis

Data was primarily analysed descriptively, as reliability of inferential statistical analyses is brought into question by small sample sizes and lack of systematic sample selection or power calculation.

Microsoft Excel was used to calculate frequencies, medians and ranges of responses to questions. Median is the most appropriate measure of central tendency for ordinal data, and means extreme values do not greatly affect overall “scores” (Allen 2012; Bowling 2002).

Frequency tables of numbers and percentages answering with different responses, and cross tabulations comparing the sites were helpful (Allen 2012). Median results for answers relating to CNS input, physical environment and peer support were charted for comparisons.

To inform our statistical analysis method, frequency polygons were constructed on Microsoft Excel, to visualise whether data was normally distributed demonstrating bell shaped curves. (Allen 2012).

Data was non-parametric; therefore a non-parametric analysis of variance was selected for inferential statistical analysis. The Kruskal-Wallis (non-parametric One-way analysis of Variance test) (KWT) was deemed most appropriate to compare data with samples above five (McDonald 2009). KWT measures variance around the median, identifying statistically significant differences by calculating a test statistic and p- value. The commonly accepted significance level for a p-value used here is 0.05. KWT tests were conducted using a reputable, online spreadsheet calculator into which we input data (McDonald 2009).

KWT is useful in telling us there is a difference between groups’ variance, but not been *which* groups. Post hoc testing with Mann Whitney tests were used to help elucidate whether any one location had a significantly different median satisfaction score for any questions found to have a statistically significant satisfaction score.

Results

Most data analysis is descriptive, as a lack of power calculation, randomisation and small sample size brings the validity of any inferential analysis into question. However, for educational purposes, we have used a Kruskal Wallis method to determine whether any statically significant difference exists between the median satisfaction scores across the three sites. Those questions found to be yield significantly different satisfaction scores across the trust were further analysed using Mann-Whitney-u post hoc testing to elucidate differences. Satisfaction with a question topic was denoted by a score of 3 (agree with positive statement) or 4 (strongly agree with positive statement).

Additonal, but less crucial data is attached in appendix B.

Findings

The number of respondents for each site were LGI n=25, TYA n=26 and Haem n=6 Σ =57.

Chart one shows the prevalence of cancers in our TYA samples. Where diagnosis was known, the most predominant were Leukaemia and Testicular cancer.

Chart one

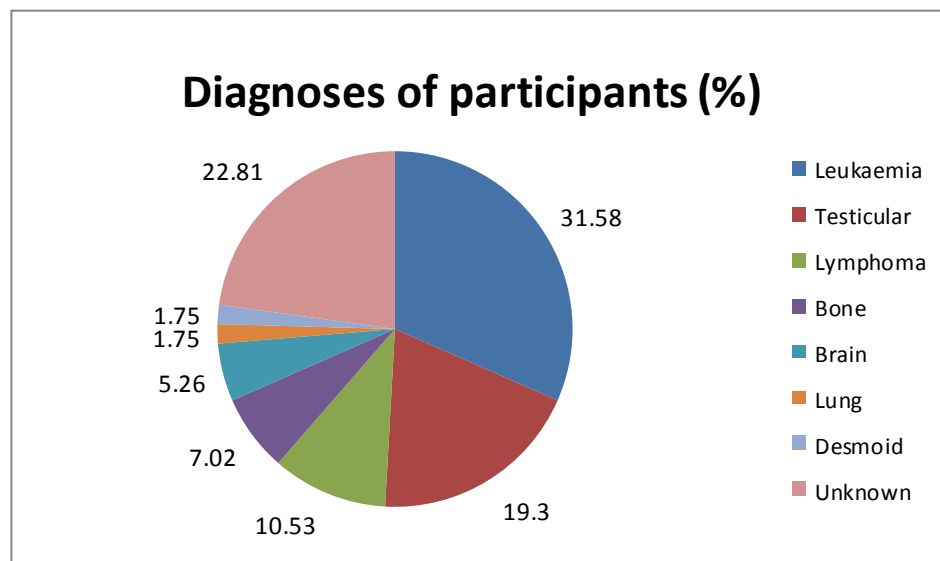


Chart two shows most respondents were male and chart three the ages of respondents across sites. It can be seen that the TYA clinic displays greatest age range, whereas those attending haematology clinic predominantly older. Also a large proportion of respondents failed to provide their age which may contribute to confounding results.

Chart two

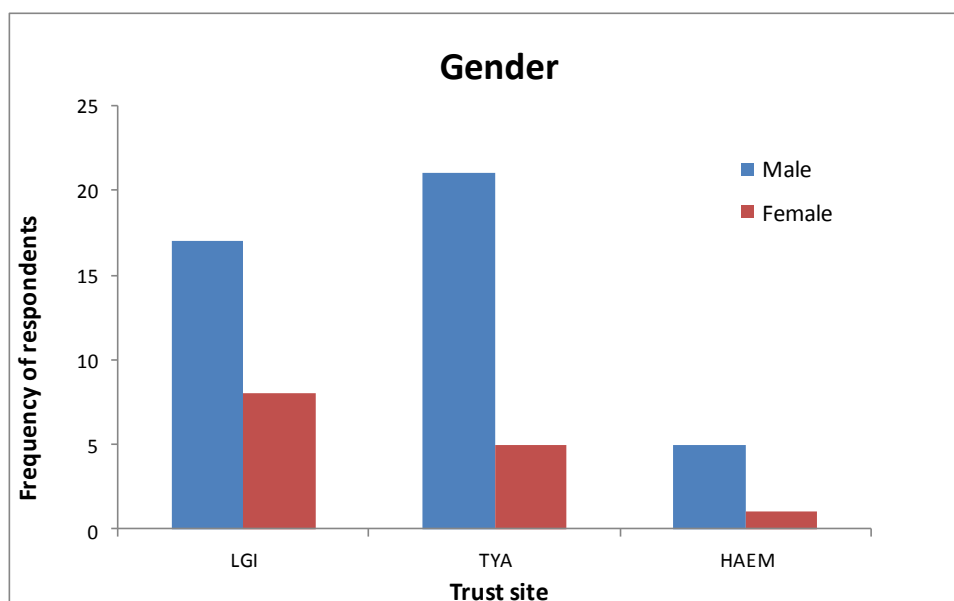
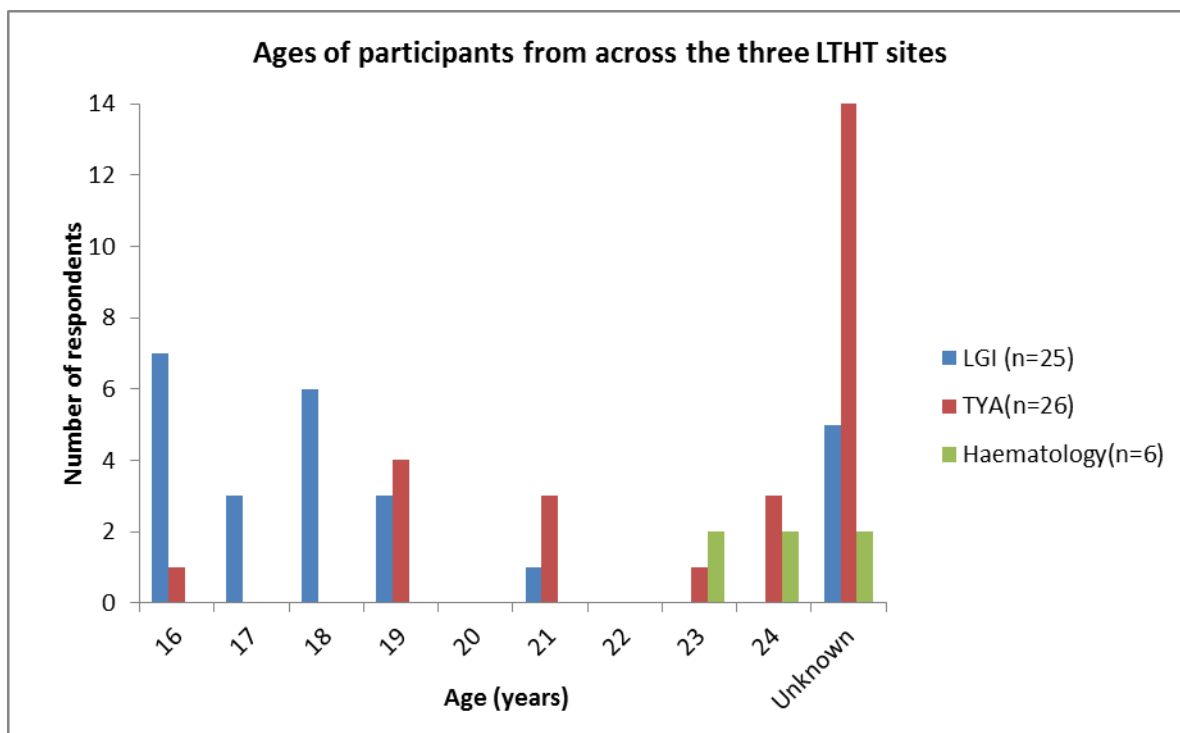


Chart three



Below are charts of composite outcomes for each of the TYA -specific domains of the service- environment (chart four) peer support, CNS input. Median satisfaction scores (one- very dissatisfied to four - highly satisfied) for each relevant question were charted to visually compare the 3 sites.

Chart four

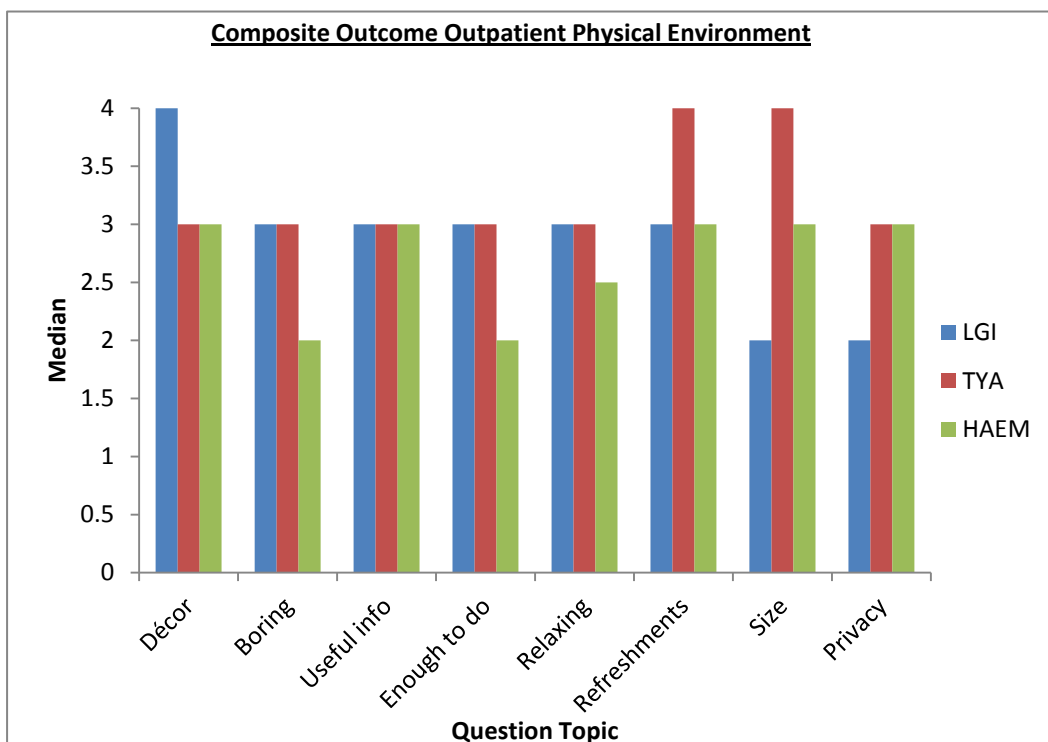


Chart 4 shows haematology patient were dissatisfied in areas of 'things to do' and 'boring clinic wait'. LGI patients were dissatisfied with room size and ability to 'have a private conversation'. Conversely it shows particular satisfaction amongst LGI patients regarding décor and amongst TYA regarding refreshments and room size.

Chart five

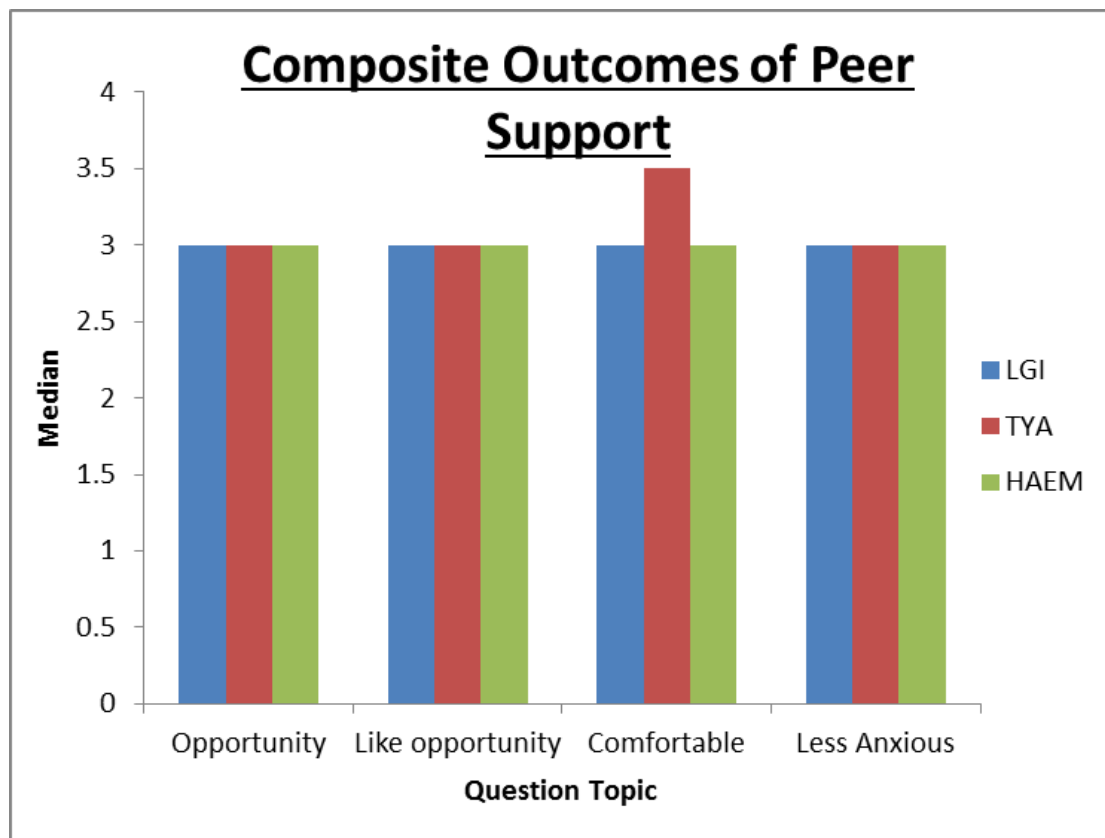


Chart 5 This Composite outcome of peer support shows satisfaction across the trust, where all felt they liked and had the opportunity to meet peers, felt comfortable and less anxious around others whilst waiting for appointments.

Chart six

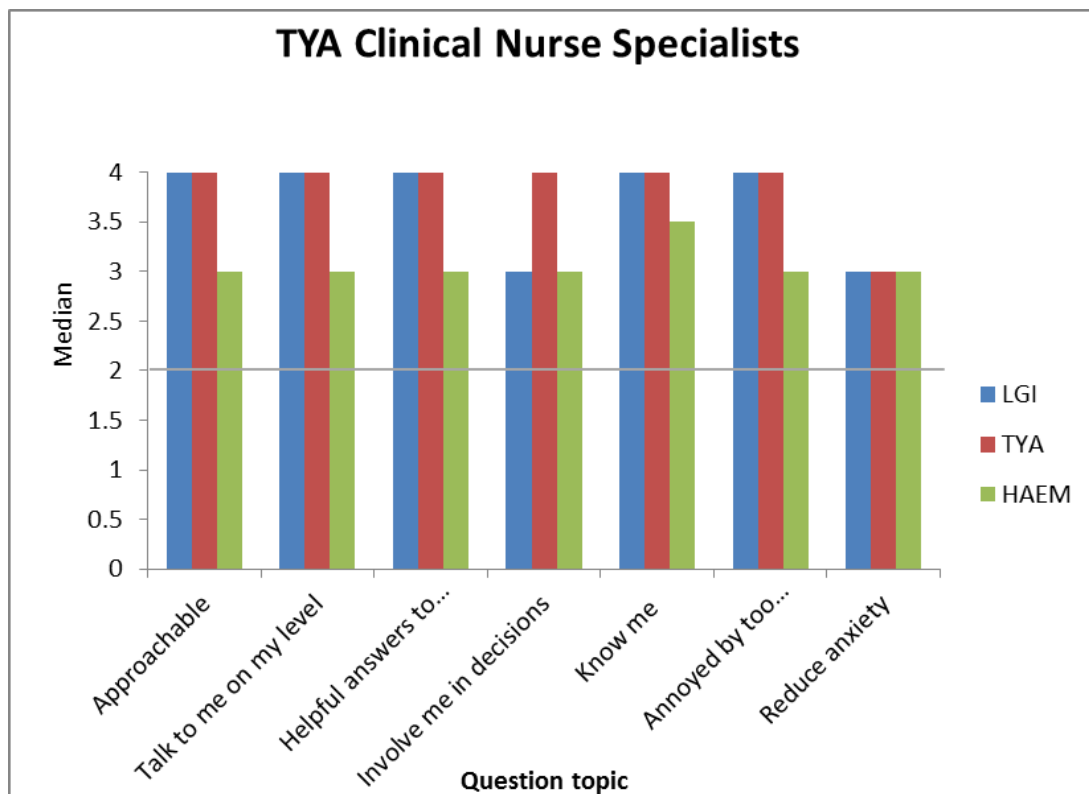


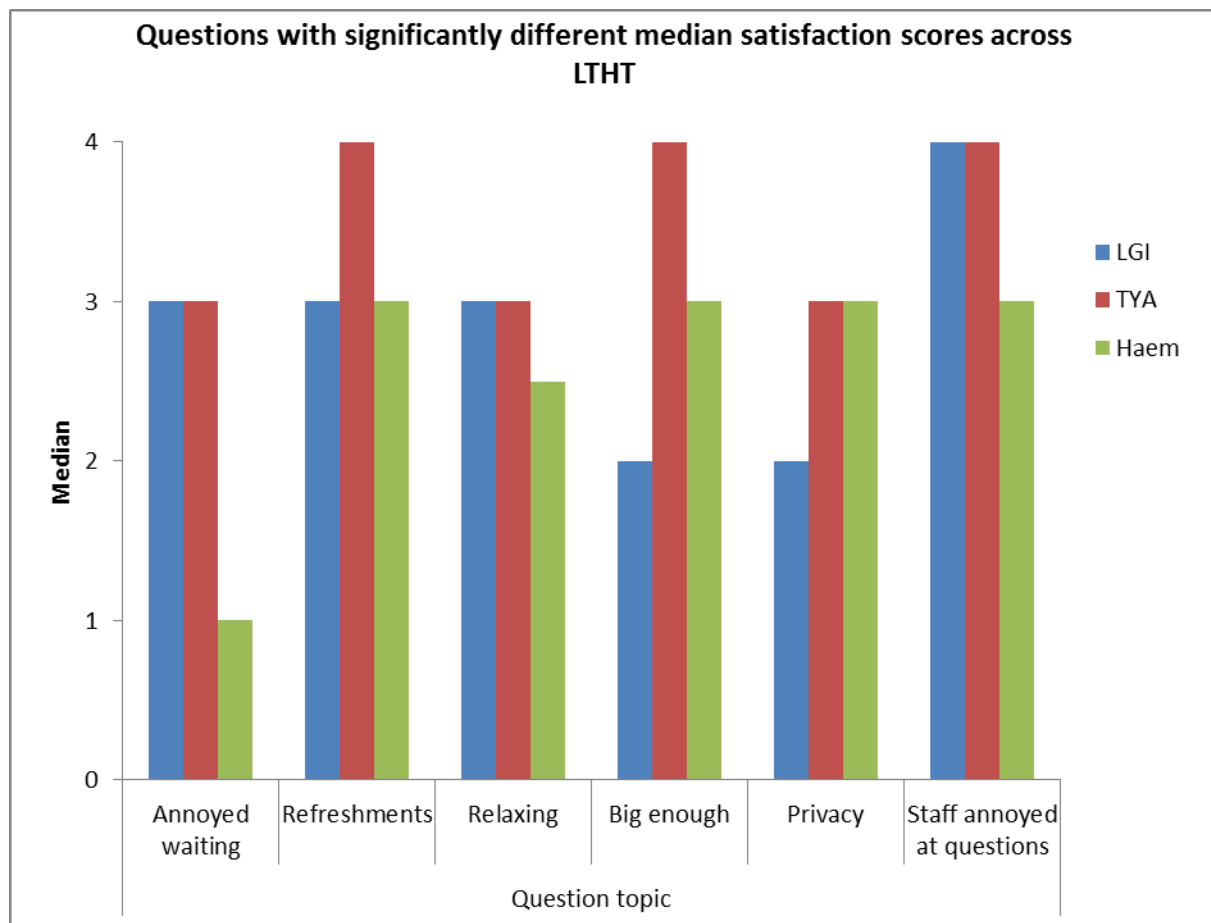
Chart 6. shows satisfaction with CNS input across the trust. All 3 sites that clinical nurse specialists were approachable, spoke to them on their level, had helpful answers to their questions, involved them in clinical decision making, knew who they were, did not get annoyed by too much questioning and helped to reduce anxiety before appointments. Satisfaction with CNS input was highest in TYA clinic.

Inferential statistics

A Kruskal Wallis analysis of the mean satisfaction score per respondent concluded that the null hypothesis (that there is no statistical difference between the median of the mean scores from the three sites) could not be rejected as $p < 0.05$ ($H = 3.49$ d.f. - 2 $p = 0.1746$). This suggests location does not have a statistically significant impact on patient satisfaction with service.

However, a more detailed analysis of satisfaction scores for each question were analysed using KWT and those where statistically significant differences were found between medians across the three sites are presented in the following chart seven, which can be used to interpret which site displayed a differing level of satisfaction.

Chart seven



A Mann Whitney-U test was selected as a post hoc test to identify whether one site, identified from the chart seven had statistically lower satisfaction score when compared with the other two sites combined. This aimed to identify if satisfaction is significantly lower in one site and if so which site may require intervention to improve satisfaction

Table one below suggest the null hypothesis of 'no difference between median scores for satisfaction between HAEM when compared with TYA and LGI (U=279, $z = -3.26$, $p = 0.0006$) could be rejected thus HAEM patients are significantly dissatisfied with waiting time when compared with other clinics.

Similarly LGI patients found to be significantly dissatisfied with the room size (U= 710 $z = -4.9$ $p < 0.0001$) and ability to have a private conversation (U= 586 $z = -2.98$ $p = 0.0014$) compared with patients in the TYA and HAEM clinics.

Question Topic	Clinics being compared		U	Z	p-value (2-tailed)
Annoyed by waiting time	HAEM	TYA + LGI	279	-3.26	0.0006
Outpatient staff get annoyed if I ask too many questions	HAEM	TYA+LGI	230	-1.99	0.0466
Refreshments available	TYA	HAEM + LGI	194.5	3.33	0.0009
Relaxing waiting room	TYA	HAEM + LGI	100	1.37	0.1707
Waiting room big enough	LGI	TYA+HAEM	710	-4.98	<0.0001
Room Big enough to talk privately	LGI	TYA+HAEM	586	-2.98	0.0014

Table one

Table one shows the test statistic, and derived p-value from the Mann-Whitney-U calculations. Those highlighted displayed a statistically significant difference when compared with other clinics combined.

Discussion

Basic, overall impression

Overall, high levels of TYA patient satisfaction with the outpatient services across LTHT.

There were 10 questions for which all respondents across all 3 sites reported a positive satisfaction score (3 or 4 with a range (3-4)) i.e none of the respondents reported dissatisfaction. This suggests that across LTHT, all patients feel staff are welcoming and supportive, put patients at ease and are happy to rearrange appointments. Similarly, they feel that all staff, including CNS, are easy to approach, talk to patients on their level, and have helpful answers to question. All also agree that they and can bring whoever they want for company during appointments.

Out of the entire evaluation, only six responses resulted in a median 'dissatisfaction' score (median score of one or two) among respondents from one of the three sites. Four of the questions were respondents from Haematology where patients felt that they were poorly informed about how long clinic waiting times would be; annoyed by the wait; bored by the waiting area and felt there was not enough to do during the wait.

The remaining two factors causing dissatisfaction were for that LGI patients felt that the room was not big enough for all TYA patients and patients felt they could not comfortably talk privately in the waiting area.

For respondents from the TYA clinic, all 40 questions answered resulted in a median score of 3 or 4, suggesting no areas of dissatisfaction.

Findings related to particular areas of interest

As stated in the aims and objectives, a key interest in this evaluation was to identify whether services were meeting the specific needs of TYA patients as documented within the literature.

The literature identified that physical environment, clinical nurse specialist input and peer support were all important to a quality TYA service, however evidence of the importance and provision of this care in the outpatient setting was lacking.

The composite outcomes charts were to visually represent the data relating to these different domains and will each be discussed.

Outpatient physical environment

Comparing responses from patients in each of the three sites, the only areas of dissatisfaction were where haematology patients were dissatisfied in terms of things to do during a wait, and LGI patients with regard to space and privacy.

Haematology waiting room lacks TYA-specific entertainments as it is primarily a generic, adult outpatient clinic whereas TYA and LGI clinics were designed with consideration for TYA holistic needs. This may explain why Mann-whitney-u test found HEAM patients were significantly unsatisfied with their waiting times compared to other sites ($U=279$, $z= -3.26$, $p=0.0006$)—as they had less age-appropriate entertainment.

The TYA clinic, although in an area of generic adult outpatient setting, is organised to bring together the age group, with a nearby television, refreshments, snacks and reading material. Similarly, the LGI waiting area is a small separated room with computer x-box and age appropriate décor. LGI were maximally satisfied with décor whilst other sites were just satisfied. This suggests that satisfaction with décor and refreshments can be achieved without investing in a TYA specifically designed environment. However, the lack of space as demonstrated in photos could explain why some LGI TYA feel hindered in having private conversations. This which may be deprive TYA of an opportunity to brooch potentially embarrassing or sensitive questions regarding their treatment with CNS or their peers. Qualitative comments on questionnaires support this.

Particular satisfaction was noted in TYA clinic with refreshments and relaxation during the wait.

Clinical nurse specialist input

There was no median dissatisfaction with any questions asked in relation to CNS at any of three sites. Haematology patients were consistently less satisfied than LGI and TYA however, possibly because CNS attendance at these clinics may be dependent whether the patient requires or requests this support.

LGI and TYA varied only on whether CNS involve patients in decision making. This could perhaps be explained by the paediatric unit practising a more family focused service than the TYA or HAEM clinics. However, this could be because the majority of LGI patients are at the lower end of the age range, thus they may lack the maturity to make autonomous decisions regarding care (Zebrak et al 2012). The fact haematology median response was the same as LGI could also mean that perhaps the TYA clinic emphasised TYA input in decision making or that the CNS are not present to contribute to decisions in Haematology.

Interestingly, all three groups scored the same for ability of CNS's to alleviate patient anxiety. This suggest that despite specialist staff and the environment tailored to TYA needs, anxieties regarding care are inevitable but that the units are a good place to be when having a bad time. TYA with cancer are likely to always have some level of anxiety (particularly waiting to see a doctor) which cannot be completely altered by the service. This is supported by some of the qualitative feed received which said 'I am always anxious about every appointment'

Anxiety is related to patient personalities and may be be unaffected by the clinic the clinic, minimising additional anxiety is important, to promote mental well being, coping and encourage treatment adherence..

Peer support

Results from all three groups did not suggest dissatisfaction in any area relating to peer support including the opportunity to meet similar people, how much they valued this and how this alleviated some anxiety. The only difference noted was that TYA group had a higher median score for feeling comfortable waiting around others in the waiting area (perhaps unsurprising as all other patients will be within the 16-24 age bracket).

The results support the literature by suggesting being around peers may contribute to patient comfort. However most literature focuses on inpatient care, whereas proximity to peers may not be as important in the outpatient environments. This is supported by the fact those waiting around adults or children in non-TYA specific environments were still satisfied. It is also important to remember that seeking peer support is highly variable and dependent upon personality, some may prefer to bring their own company and not socialise, whilst others may seek out others with cancer to share their anxieties. Furthermore patients may seek peer support from sources other than the outpatient waiting room– they may look to structured peer support

activities, online social networks e.g. Jimmy Teens or perhaps more likely develop form relationships during prolonged inpatient stays.

We expected haematology patients to express more desire to meet peers as they are treated separately from the other TYAs. However, this may be confounded by the fact that the haematology patients were older (19-24 years), thus perhaps more mature or closer in age to others in the waiting room, thus less likely to feel alienated than a 16 year old, for example.

Comparison with existing literature

The common factor throughout all three sites of TYA outpatient care is the input of CNS. This study would support a recent high quality systematic review and meta-synthesis of qualitative research discussing the impact of TYA staff on patient experience being as important as physical surroundings (Taylor et al. 2012). LTHT CNS are meeting aims of key worker roles described in literature by co-ordinating personalised care, support and advice to patients and families (Leeds Teaching Hospital NHS Trusts 2012; Teenage Cancer Trust 2012b; NICE 2005).

TYA have consistently emphasised the benefits derived from peer support in their cancer journey (Smith et al 2007) especially as they develop into autonomous adults guided by friends and family (Zebrak et al 2012). When cancer stigmatises them amongst non-ill friends, seeking cancer peer support improves self esteem; treatment adherence and coping; promoting normalcy and transition into survivorship. Some feel they can only share certain anxieties e.g. future fertility, preoccupations about appearance with others 'in the same boat' who understand what they are going through (Coccia et al 2012; Butow et al 2010). Outpatient clinics may provide opportunities for such encounters or discussions. However, our evaluation suggested LGI patients felt room size hindered private conversations, potentially depriving TYA opportunities to share anxieties either with peers or CNS. There was satisfaction across the board with access to peer support, even in Haematology. Therefore it may be that being comfortable 'in the same boat' during outpatients could be irrespective of how old others are. It could also be explained by the fact haematology patients were at the older end of our age bracket. Further research into whether these patients choose to talk to other patients or who they attend clinic with would be interesting, as they may get peer support from other sources e.g. facebook or Jimmy Teens.

Method limitations and further research required

Overall satisfaction scores

Although working out overall mean satisfaction scores for patients at the three sites was deemed useful, this data presented is of limited value and should be interpreted with caution. Missing data may have skewed the results by omission of high or low scoring responses i.e. strong opinions. Additionally, some responses to questions appeared contradictory suggesting 'question fatigue'.

Furthermore, the mean satisfaction score does not correct for unequal weighting of the questions, e.g. access to refreshments is unlikely to be equally valued access to staff who are approachable.

Due to data skew towards high satisfaction scores, it is accepted that participants are generally satisfied, but it is difficult to distinguish those who are 'satisfied' from those who "could not be more satisfied" for example.

It is also important to remember satisfaction is affected by extraneous factors independent of the clinic services e.g patient temperament, or appointment purpose (e.g to receive test results) could yield falsely high or low satisfaction scores.

Sampling

There can be more confidence placed in descriptive analysis presented than the inferential statistics. Convenience sampling is considered to have high potential for bias in being non-randomised (Allen 2012). Results were analysed by novice quantitative researchers over a limited timeframe, on a small sample which likely lacks power to demonstrate confidently statistically significant results. Any significant or non-significant differences would be more confidently reported with increasing sample size and therefore representativeness of TYA using LTHT outpatient services. More participants may also reveal statistically significant differences not currently identifiable (Allen 2012). Unfortunately we did not have SJUH TYA or LGI clinic lists of participants in our age range, and receptionists discarded clinic lists once used, therefore we ideally would want to know overall population size and dropout rate if we were to repeat the evaluation.

Questionnaire

A ceiling effect demonstrated in the data (large quantities of three and four scores) may have been avoided by using a wider likert scale. This would have helped discern the variations in how satisfied patients are, however results may have returned similar just because the service is considered highly satisfactory. Additionally, expanding likert scales could affect participation by too being too much effort to complete.

Missing demographics may be because patients did not want to be identified with their responses when handing questionnaires to receptionists. Using a returns box would perhaps have helped. Perhaps the questionnaire needed clearer presentation. Some double-sided pages were missed as they were without 'PTO' instructions. Although refuted in pilots, another explanation for missing data could be questionnaire length (40 statements) causing respondent fatigue.

Response rate may be improved by researchers being present to facilitate questionnaire completion. Tick box demographics options would have helped ensure inclusion criteria e.g. age range are confidently met. Results are increasingly considered biased where data is missing (Allen 2012).

Although some qualitative comments were made in the comments box, this was minimal, with statements more than constructive improvement suggestions. Qualitative interviews or focus groups could stimulate in-depth discussion (allowing respondents rather than researchers to guide feedback topics) regarding satisfaction and improvements (Watson & Coombes 2009).

Potential improvements to service

The haematology TYA satisfaction may be enhanced by simple measures such as staff making efforts to update patients on expected waiting times on arrival or where delays arise. A more expensive change could perhaps be some kind of electronic system displaying waiting times which would also benefit other patients. Providing more age-appropriate reading material and notice boards in haematology clinics could be an easy and inexpensive way of improving “things to do” during waits.

In contrast, to enhance LGI TYA satisfaction, room size issues are less easy changed. Perhaps this work can provide some evidence to efforts to expand it in future. A cost-benefit analysis would need to be conducted to work out how much improved satisfaction would result from these expensive changes in an already highly satisfied group.

Public health implications

Service evaluations are important to facilitate communication between service users and providers and ensure services are meeting expectations, well-evidenced and cost-effective. Evaluations provide evidence to improve practice and policies, and even when small-scale, are important to inform simple, local changes which could exponentially improve patient satisfaction (Allen 2012). As future practitioners, striving to provide patient-centred, evidence-based care requires taking responsibility for monitoring service quality and developing service evaluation skills.

This evaluation demonstrated high satisfaction with TYA oncology outpatient clinics across LTHT, which take place in different locations- not necessarily TYA-specific physical environments. This is a valuable finding as rising incidence of TYA cancer mean it is unrealistic to expect trusts to always provide TYA-specific *outpatient* clinics. Staff can be reassured they still provide satisfactory TYA services.

The literature is clear that TYA-specific services are fundamental in prolonged inpatient care. However during short outpatient stays, this evaluation suggests satisfaction is still attained in non TYA-specific settings. Therefore investing large amounts of money into specialist TYA outpatient units may not be imperative in a financially restricted NHS. We acknowledge patients in TYA-specialist clinics have higher satisfaction in some domains evaluated, but TYA attending other clinics are still largely satisfied with service received. Considering whether expensive interventions for small incremental satisfaction improvements are required in services already deemed predominantly satisfactory. We suggest some small measures to potentially improve satisfaction. Further research evaluating the

expense of LGI waiting room enlargement with potential satisfaction improvement would be interesting. We agree with research suggesting that quality TYA care may be achievable in non-specialist environments, by establishing TYA “atmospheres” (Marris, Morgan & Stark 2010; Grinyer 2007).

CNS roles are increasing (Royal College of nursing 2010; 2004). CNS input is common across all studied sites and was the only “domain” where all median responses were satisfactory. This provides some evidence to how TYA value CNS across LTHT. Literature advocates CNS as important bridges between non-specialist and specialised TYA facilities (Morgan et al. 2010; Pearce 2009 & NICE 2005). CNS involvement in TYA cancer care is a quality measure, and is important to prevent impaired psychosocial development, which has human and financial medical costs (National Cancer Action Team 2011). Wider literature suggests CNSs are cost-effective in delivering TYA care to more patients amongst a variety of backdrops (Morgan et al. 2010; Royal College of Nursing 2010; Pearce 2009; NICE 2005).

Conclusion

Cancer incidence is rising but so is survivorship, therefore TYA cancer care is an important public health issue. To improve TYA cancer outcomes, age-appropriate services with CNS involvement and suitable physical environments can contribute to better patient experience, minimising negative impacts on TYA psychosocial development (Smith et. al 2012; Morgan et al. 2010; Woodgate 2006; NICE 2005; Ritchie 2001). There has to be maintained focus on evaluating and assessing whether services meet specific TYA needs.

To evaluate current quality of LTHT TYA oncology outpatient services, a questionnaire survey assessed patient satisfaction at three sites: LGI paediatric outpatient unit, SJUH TYA clinic and haematology adult outpatients.

TYA satisfaction with outpatient services was consistently high. Areas causing dissatisfaction were lack of age-appropriate information; annoyance with waiting times and boredom during haematology clinics in generic, adult outpatient settings. The only other dissatisfaction was with LGI paediatric waiting room size and affects on ability to talk privately.

No dissatisfactory areas were identified in patients attending SJUH TYA-specific clinic, held in generic outpatients settings.

Findings suggest TYA receiving outpatient oncology care across LTHT in non-TYA-specific environments and without exclusive TYA clinic lists can still be highly satisfied, potentially because of CNS input cross sites. This could also be related to age-appropriate care being less important for short time periods spent in outpatient clinics. Further research identifying perceived satisfaction improvement with changes implemented; research balancing money investments into enlarging LGI waiting area with potential gain in patient satisfaction and increasing sample sizes would help to

elicit further understanding. Realistic improvement suggestions are small measures such as TYA-appropriate reading materials in haematology clinics.

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References

ALLEN, A.K. 2012. *Research Skills for Medical students*. London: SAGE.

BOWERS, D., HOUSE, A & D.OWENS. 2011. *Getting started in Health Research*.Oxford: Wiley-Blackwell.

BOWLING, A.2002. *Research Methods in Health: Investigating Health And Health Services*. Berkshire: Open University Press.

CALMAN HINE 1995. *A policy framework for commissioning cancer services : A report by the Expert Advisory Group on Cancer to the Chief Medical Officers of England and Wales*.The Expert Advisory Group on Cancer to the Chief Medical Officers of England and Wales 1 April 1995. Calman Hine report (1995) Crown Copyright

DEPARTMENT OF HEALTH *Department for Education and Skills 2004 National Service Framework for Children, Young People and Maternity Services: Children and young people who are ill*. [Online] London Crown Copyright [Accessed 13th Feb 2013] Available from http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_4104032.pdf

DEPARTMENT OF HEALTH 2010 *Equity and excellence: Liberating the NHS* Crown [Online] London Crown Copyright [Accessed 11th March] Available from http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_117353

GRINYER, A. 2007. *Young People Living with Cancer. Implications for Policy and Practice*. Berkshire: Open University Press

KIRKLEES COUNCIL. *Research and Consultation Guidelines- Questionnaires* [online]. N.D. [Accessed 18th February 2013]. Available from: <http://www.kirklees.gov.uk/community/yoursay/Questionnaires.pdf>

McDonald, JH. *Kruskal- Wallis test and Mann-Whitney U Test* [online]. 2009. [Accessed 20th February 2013]. Available from: <http://udel.edu/~mcdonald/statkruskalwallis.html>

MARRIS, S., S. MORGAN & D. STARK. 2011. 'Listening to Patients': what is the value of age-appropriate care to teenagers and young adults with cancer? *European Journal of Cancer Care* [online]. **20**(2), [Accessed 12th September 2012], pp. 145-151. Available from: <http://onlinelibrary.wiley.com/doi/10.1111/j.1365-2354.2010.01186.x/abstract;jsessionid=3B090C261F377E2A2E37002E32C8B655.d01t03>

MORGAN, S., S. DAVIES, S. PALMER & M. PLASTER. Sex, drugs and rock 'n' roll: caring for adolescents and young adults with cancer. *Journal of Clinical Oncology*. 2010. **28**(32), pp. 4825- 4830.

NATIONAL PATIENT SAFETY AGENCY. 2009. *National Research Ethics Service: Defining Research* [online]. 2009. [Accessed 24th February 2013]. Available from: <http://www.nres.nhs.uk/applications/is-your-project-research/>

NATIONAL INSTITUTE FOR HEALTH AND CLINICAL EXCELLENCE, Guidance on Cancer Services. 2005. *Improving outcomes in children and young people with cancer: The Manual* [online]. [Accessed 17th September 2012]. Available from: <http://www.nice.org.uk/nicemedia/live/10899/28876/28876.pdf>

NATIONAL CANCER ACTION TEAM – NATION CANCER PEER REVIEW 2011 *Manual for Cancer Services: Teenagers and Young Adults Measures* [Online]

LONDON [Accessed 16th March 2013] Available:

http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_128071.pdf

O'HARA, C., A MORAN (NWCIS) AND THE TYA NATIONAL CANCER INTELLIGENCE ADVISORY GROUP. 2012. *Survival in Teenagers and Young Adults (TYA) with Cancer in the UKA comparative report comparing TYA cancer survival with that of children aged 0 to 14 years and adults aged 25 to 49 years and looking at differences in survival by gender*. [Online]. [February 22nd 2013] Accessed via www.ncin.org.uk/view.aspx?rid=1607

PEARCE, S. 2009. Policy and practice in teenage and young adult cancer care in England: Looking to the future. *European journal of Oncology Nursing* [online]. **13**(3), [Accessed 22nd September 2012], pp. 149- 153. Available from:

<http://www.sciencedirect.com/science/article/pii/S1462388909000660>

PHILLIPS, R., ABSOLOM, K., STARK, D. & A. GLASER. A simple, practical patient-reported clinic satisfaction measure for young adults. *British Journal of Cancer* [online]. 2010. 103, pp.183-1488. [Accessed 2nd December 2012]. Available from: http://www.researchgate.net/publication/47729830_A_simple_practical_patient-reported_clinic_satisfaction_measure_for_young_adults

PLATT SH 1959 The Welfare of Children in Hospital *British Medical Journal* [Online]. 1 (5115) [Accessed 11th February 2013] pp 166-169 Available from : <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1992241/>

RITCHIE, M. 2001. Psychosocial nursing care for adolescents with cancer. *Issues in Comprehensive Pediatric Nursing* [online]. 24(), [Accessed 22nd October 2012], pp 165-175. Available from:

<http://www.ingentaconnect.com/content/apl/ucpn/2001/00000024/00000003/art0000>

ROYAL COLLEGE OF NURSING. 2004. Services for children and young people: preparing nurses for future roles [online]. [Accessed 23rd September]. Available from: http://www.rcn.org.uk/__data/assets/pdf_file/0003/78627/002454.pdf

Royal College of Nursing. 2010. *Specialist nurses: Changing lives, saving money* [online]. [Accessed 23rd September] . Available from: http://www.rcn.org.uk/__data/assets/pdf_file/0008/302489/003581.pdf

ROYAL COLLEGE OF PHYSICIANS. *How User friendly is Your Outpatient department?* [Online]. 2004. [Accessed 19th February 2013.] Available from : <http://bookshop.rcplondon.ac.uk/contents/e608649f-321c-43a3-a132-31514157e371.pdf>

SMITH, S. et al. 2012. *A Blueprint of care for Teenagers and Young Adults with Cancer* [online]. [Accessed 22th September 2012]. Available from: <http://www.teenagecancertrust.org/what-we-do/health-professionals/blueprint-of-care/>

TAYLOR, M.R., S. PEARCE, F. GIBSON, L. FERN, J. WHELAN. 2012. Developing a conceptual model of teenage and young adult experiences of cancer through meta-synthesis [online]. *International Journal of Nursing Studies*. No issue number. Available from: <http://0-dx.doi.org.wam.leeds.ac.uk/10.1016/j.ijnurstu.2012.09.011>

TEENAGE CANCER TRUST. TEENAGE CANCER TRUST FACTSHEET [Online]. 2012. [Accessed 21st February 2013] Available from: <http://www.teenagecancertrust.org/workspace/documents/Teenage-Cancer-Trust-Factsheet-December-2012.pdf>.

TEENAGE CANCER TRUST FEEDBACK ON DEPARTMENT OF HEALTH 'CHILDREN AND YOUNG PEOPLE'S HEALTH OUTCOMES STRATEGY' [Online] 2012 [Accessed 12 March 2013] Available from:

<http://www.teenagecancertrust.org/workspace/documents/TeenageCancerTrust-CYPHealthOutcomesStrategy2.pdf>

TEENAGE CANCER TRUST. 2012b. Meet the Nursing Team [online]. [Accessed 26 September 2012]. Available from: <http://www.teenagecancertrust.org/what-we-do/health-professionals/our-unit-staff/nurses/>

WATSON, M. & L. COOMBES. 2009. Surveys. In: NEALE, J. *Research Methods for Health and Social Care*. Hampshire: Palgrave Macmillan, pp.121-136.

WILSON, A., HEWITT, G. MATTHEWS, R. , RICHARDS, S.H. & S.SHEPPERD. Development and testing of a questionnaire to measure patient satisfaction with intermediate care. *Qual Saf Health Care* [online]. 2006.**15**(5), [Accessed 2nd March 2013], pp.314-319.available from:<http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2565811/>

WOODGATE, R.L. 2006. The Importance of being there: perspectives of social support by adolescents with cancer. *Journal of Pediatric Oncology Nursing* [online]. **23**(3), [Accessed 21st September 2012], pp. 122-134. Available from: <http://jpo.sagepub.com/content/23/3/122.long>

Appendix A

The purpose of this questionnaire is to compare general outpatient services with age-specific outpatient services for teenagers and young adults diagnosed with cancer in Leeds, with an aim to improving services in the future.

Nobody will know these are your answers and what you say will not affect your care at all.

Please help us by filling in this short questionnaire

Please circle which outpatient clinic you have come to:

Leeds General Infirmary

St James' TYA outpatient clinic

St James' haematology clinic

Age:

Gender: Male Female

I have been diagnosed with:

It has been:..... months/ years since I was diagnosed

Instructions

Please tick the single most relevant box as an answer to the following questions.

e.g.

Strongly agree

Agree

Disagree

Strongly disagree

Before coming to this outpatient clinic, I:				
	Strongly agree	Agree	Disagree	Strongly disagree
Find the information in my appointment letter helps me prepare.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Find the information in my appointment letter makes me feel less anxious.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Find it easy to rearrange appointments if needed.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Feel staff are happy to help me change any appointments.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Am happy to make the journey to clinic	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Arriving in the outpatient clinic, I feel:				
	Strongly agree	Agree	Disagree	Strongly disagree
Staff are welcoming and supportive.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Staff put me at ease.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am told how long I may have to wait.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The clinic is flexible enough to let me leave and return closer to my appointment time	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

	Strongly agree	Agree	Disagree	Strongly disagree
I get annoyed by the waiting time.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I can bring whoever I want to keep me company.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The clinic's waiting room:				
	Strongly agree	Agree	Disagree	Strongly disagree
Is decorated acceptably.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Is boring.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Contains useful information about things I want to know.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Has enough things for me to do to whilst waiting.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Does not stop me using my mobile phone if I want to.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Has refreshments available.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Is relaxing before seeing the doctor.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Is big enough for all the patients waiting for appointments	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Still allows me to talk privately without	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

being overheard				
During outpatient clinic waits, I:				
	Strongly agree	Agree	Disagree	Strongly disagree
Have the chance to meet and talk to others in the same situation.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Like being able to meet other patients.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Am comfortable waiting with the other patients.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Less anxious when I am waiting with other patients.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
During clinic, the clinical nurse specialists:				
	Strongly agree	Agree	Disagree	Strongly disagree
Are easy to approach if I want to talk.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Talk to me on my own level.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Have helpful answers to questions that I have	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Involve me in making decisions.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Know who I am and	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

about me				
	Strongly agree	Agree	Disagree	Strongly disagree
Get annoyed if I ask too many questions	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Make me feel less anxious	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
In the outpatient clinic, I feel the other staff members:				
	Strongly agree	Agree	Disagree	Strongly disagree
Are easy to approach if I want to talk.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Talk to me on my own level.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Have helpful answers to questions that I have	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Involve me in making decisions.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Know who I am and about me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Get annoyed if I ask too many questions	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Make me feel less anxious				
After outpatient clinics, I:				
	Strongly agree	Agree	Disagree	Strongly disagree
Know who I can contact after clinic if I want more support.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Can easily get in touch with someone from clinic if I want to.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Any comments about the waiting room space, patients around you, nurses or your time in outpatients

Thank you! Please hand this back to the receptionist.

Appendix B

Table 2 Shows the Age of respondents and which outpatient clinic they attend

Age of Respondent	LGI (n=25)	TYA (n=26)	HAEM (n=6)
16	7 (28%)	1 (3.9%)	-
17	3 (12%)	-	-
18	6 (24%)	-	-
19	3 (12%)	4 (15.4%)	-
20	-	-	-
21	1 (4%)	3 (11.5%)	-
22	-	-	-
23	-	1 (3.9%)	2 (33.3%)
24	-	3 (11.5%)	2 (33.3%)
Unknown	5 (20%)	14 (53.8%)	2 (33.3%)

Table 3 Shows the which cancer diagnosis the respondents have received.

Diagnosis	Number of respondents (n=57)	Percentage of respondents (%)
Leukaemia	18	31.58
Testicular	11	19.3
Lymphoma	6	10.53
Bone	4	7.02
Brain	3	5.26
Lung	1	1.75
Desmoid	1	1.75
Unknown	13	22.81

Table 4 Shows the median satisfaction scores for each question for each clinic and the corresponding results of the Kruskal-Wallis Test for each question. Highlighted in yellow are the questions found to have statistically significant difference between satisfaction across the 3 sites. Highlighted in green are the questions which resulted in patient dissatisfaction.

Question number	Question topic	Median satisfaction score (minimum-maximum response)			Kruskal-Wallis results (to 2 degrees of freedom)	
		LGI	TYA	HAEM	H-value	P-value
1	Pre-clinic information helps prepare	4 (2-4)	3 (2-4)	3 (3-4)	0.616	0.735
2	Pre-clinic information eases anxiety	3 (2-4)	3 (1-4)	3 (2-4)	2.743	0.254
3	Easy to rearrange appointments	4 (3-4)	3 (1-4)	3.5 (2-4)	0.615	0.735
4	Staff happy to rearrange	4 (3-4)	4 (3-4)	4 (3-4)	0.869	0.647
5	Happy to make journey to clinic	3 (3-4)	4 (2-4)	3 (2-4)	0.728	0.695
6	Welcoming and supportive staff	4 (3-4)	4 (3-4)	4 (3-4)	0.457	0.796

7	Staff put at ease	4 (3-4)	4 (3-4)	4 (3-4)	0.471	0.79
8	Told how long will wait is	3 (1-4)	3 (1-4)	1 (1-4)	2.447	0.294
9	Flexible to leave and return	3 (2-4)	3 (1-4)	3 (2-4)	1.376	0.503
10	Annoyed by waiting time	3 (1-4)	3 (1-4)	1 (1-2)	11.923	0.002576
11	Can bring whoever as company	4 (3-4)	4 (3-4)	4 (3-4)	1.141	0.565
12	Decorated acceptably	4 (3-4)	3 (1-4)	3 (3-4)	2.456	0.293
13	Boring	3 (1-4)	3 (1-4)	2 (1-3)	2.875	0.238
14	Useful information	3 (2-4)	3 (2-4)	3 (3-4)	1.88	0.391
15	Enough to do during wait	3 (2-4)	3 (2-4)	2 (1-4)	4.134	0.127
16	Does not stop mobile use	4 (2-4)	4 (2-4)	4 (2-4)	1.239	0.538
17	Refreshments available	3 (1-4)	4 (2-4)	3 (2-4)	13.771	0.001023
18	Relaxing	3 (1-4)	3 (2-4)	2.5 (1-4)	6.079	0.048
19	Big enough room	2 (1-4)	4 (2-4)	3 (3-4)	28.255	7.32x10⁻⁷
20	Can talk privately	2(1-4)	3 (2-4)	3 (3-4)	10.512	0.005216
21	Chance to meet and talk to similar others	3 (2-4)	3 (2-4)	3 (2-4)	2.226	0.329
22	Like meeting others	3 (1-4)	3 (1-4)	3 (3-4)	1.366	0.505
23	Comfortable waiting with others	3 (1-4)	3.5 (3-4)	3 (3-4)	5.594	0.061
24	Less anxious waiting with others	3 (1-4)	3 (2-4)	3 (3-4)	1.849	0.397
25	CNS easy to approach	4 (3-4)	4 (3-4)	3 (3-4)	2.741	0.254
26	CNS talk to me on my level	4 (3-4)	4 (3-4)	3 (3-4)	1.977	0.372
27	CNS have helpful answers to questions	4 (3-4)	4 (3-4)	3 (3-4)	1.574	0.455
28	CNS involve me in decisions	3 (3-4)	4 (2-4)	3 (2-4)	2.674	0.263
29	CNS know me	4 (2-4)	4 (3-4)	3.5 (3-4)	1.901	0.386
30	CNS annoyed by questions	4 (2-4)	4 (2-4)	3 (1-4)	5.43	0.066
31	CNS make me less anxious	3 (2-4)	3 (1-4)	3 (3-4)	0.937	0.626
32	Other staff easy to approach	4 (3-4)	4 (3-4)	3 (3-4)	4.112	0.128
33	Other staff talk on my level	4 (3-4)	4 (3-4)	3 (3-4)	3.608	0.165
34	Other staff have helpful answers	4 (3-4)	4 (3-4)	3 (3-4)	3.108	0.211
35	Other staff involve me in decisions	3 (3-4)	3.5 (2-4)	3 (2-4)	4.407	0.11
36	Other staff know me	3 (2-4)	3 (1-4)	3 (3-4)	1.529	0.466

37	Other staff annoyed by questions	4 (2-4)	4 (2-4)	3 (1-3)	9.146	0.01
38	Other staff make me less anxious	3 (2-4)	3 (2-4)	3 (2-4)	1.245	0.537
39	Know a post-clinic support contact	4 (2-4)	4 (2-4)	3 (3-4)	4.981	0.083
40	Easy to get in touch with clinic contact	4 (2-4)	4 (2-4)	3 (3-4)	4.021	0.134

The Following tables 5 - 9 represent the median scores used to construct the relevant composite outcomes graphs.

Clinical Nurse Special (CNS)	Clinic Location Median Satisfaction Score (1 very dissatisfied – 4 highly satisfied)			
	Question Topic	LGI	TYA	HAEM
	Approachable	4	4	3
	Talk to me on my level	4	4	3
	Helpful answers to my questions	4	4	3
	Involve me in decisions	3	4	3
	Know me	4	4	3.5
	Annoyed by too many questions	4	4	3
	Reduce anxiety	3	3	3

Outpatient Physical Environment	Clinic Location Median Satisfaction Score (1 very dissatisfied – 4 highly satisfied)			
	Question Topic	LGI	TYA	HAEM
	Décor acceptable	4	3	3
	Boring whilst waiting	3	3	2
	Useful information in waiting room	3	3	3
	Enough to do whilst waiting	3	3	2
	Relaxing whilst waiting	3	3	2.5
	Refreshments	3	4	3
	Large enough waiting room	2	4	3
	Large enough to have a private conversation	2	3	3

Peer support	Clinic Location Median Satisfaction Score (1 very dissatisfied – 4 highly satisfied)			
	Question Topic	LGI	TYA	HAEM
	Opportunity to meet peers	3	3	3
	Would like opportunity to meet peers	3	3	3
	Comfortable waiting with others	3	3.5	3
	Less Anxious waiting with others	3	3	3

Outpatient Staff	Clinic Location Median Satisfaction Score (1 very dissatisfied – 4 highly satisfied)		
	Question Topic	LGI	TYA
Approachable	4	4	3
Talk to me on my level	4	4	3
Helpful answers to my questions	4	4	3
Involve me in decisions	3	3.5	3
Know me	3	3	3
Annoyed by too many questions	4	4	3
Reduce anxiety	3	3	3

Outpatient Logistics	Clinic Location Median Satisfaction Score (1 very dissatisfied – 4 highly satisfied)		
	Question Topic	LGI	TYA
Information letter helps prepare for clinic	4	3	3
Information letter helps reduce anxiety	3	3	3
Find it easy to rearrange appointments	4	3	3.5
Staff are helpful	4	4	4
Patients are happy to travel to clinic	3	4	3
Welcoming staff	4	4	4
Staff put patient at ease	4	4	4
Informed of waiting time	3	3	1
Can leave waiting and return nearer appointment time	3	3	3
Annoyed by the waiting time	3	3	1
Can bring company for the appointment	4	4	4
Know who to contact for more support	4	4	3
Easy to contact staff for more support	4	4	3

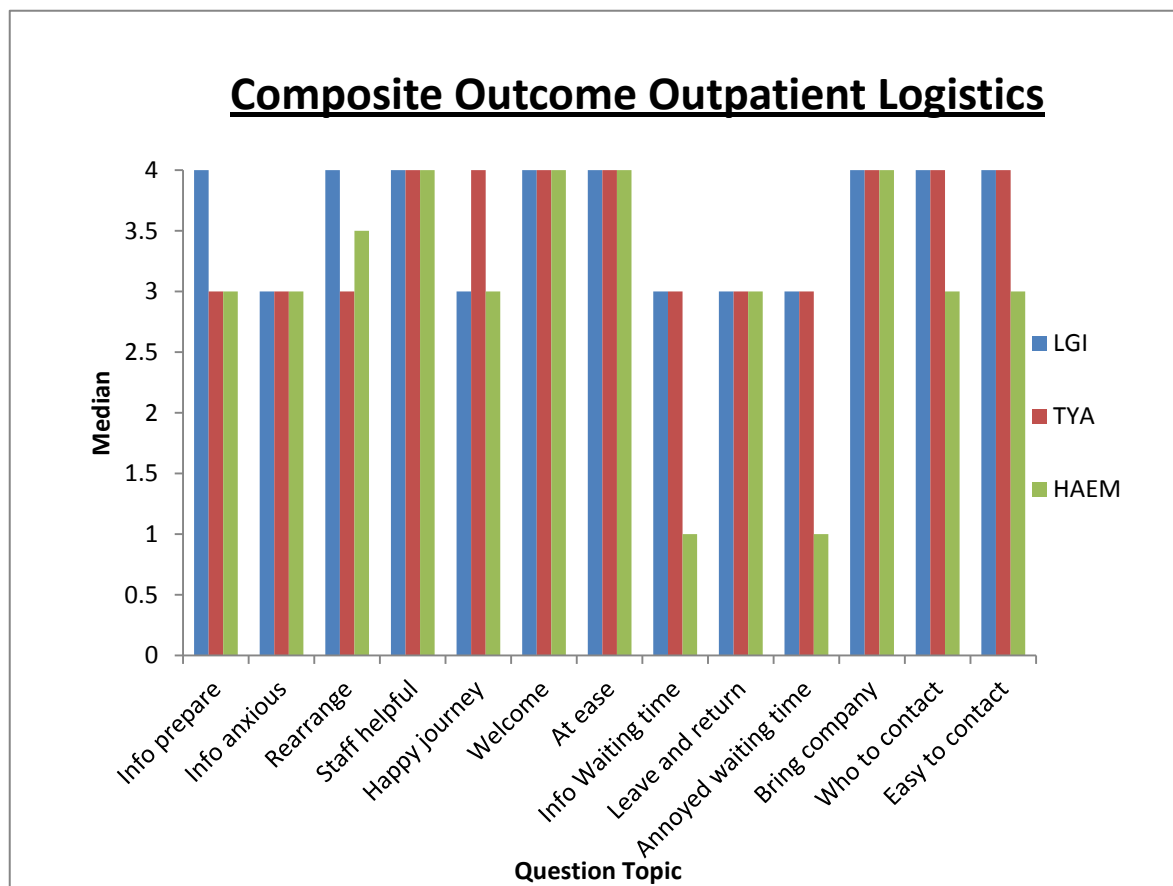


Chart 8 Above is a graph of the corresponding composite outcome data for the outpatient logistics. Median values are plotted, as per previous outcome graphs.