

**Title:** ***“Empowering young people”: An examination of the work of the National Health Service [NHS] England Youth Forum***

**Abstract:**

*Aim:* To examine the role of NHS England Youth Forum [NHSEYF] members and the strategies undertaken to influence health service provision for children and young people.

*Method:* An evaluative mixed methods research study (commissioned by NHS England and undertaken by the University of Hertfordshire, July 2015 - September 2016) was undertaken. Data collection comprised of Activity Logs (a form of questionnaire) as well as semi-structured interviews.

*Findings:* The analysis of the Activity Logs revealed that the young people were undertaking a wide range of activities across England. Seven themes emerged from the interviews: *The young people; motivation; commitment; community (the local area as well as a community spirit); funding; knowledge experts; youth workers*. In summary, the members of the NHSEYF were totally committed to their role; importantly, their work was having a positive impact on health service provision.

*Conclusion:* The NHSEYF has developed rapidly and successfully; most notably, it is enabling the voice of young people to be heard.

**Keywords:** Youth forum; young people; youth voice; NHS England.

**Introduction and background**

NHS England (2015: 5) suggests that a youth forum’s key role is to “*represent the views of young people*” and to “*contribute to improving and developing services for young people.*”

Whilst there is little previous research that has focussed on youth forums/councils, two studies are worthy of note. A survey of four youth councils in the East Midlands, England was undertaken by Matthews (2001); sixty-three young people were involved in either an individual semi-structured interview or a focus group in order to gain insight into their perceptions of being part of a youth council. The research identified several positive aspects, including improved appreciation of local issues, the ability to make a difference as well as personal development. However, several of challenges were also acknowledged: The associated bureaucracy, not having the required authority, being tokenistic, not having enough time to time to complete the intended outcomes, not having members from diverse backgrounds, and, importantly, not being wholly

representative of the young people's views. The study concluded that consideration needed to be given to the facilitation of youth councils, especially in respect of the *"initiation, the process and the outcome of young people's participation"* (Matthews, 2001: 309).

Collins et al (2016) undertook research that focussed on youth councils in an urban area in the United States of America; the participants were adult representatives with one person from each of twenty-four neighbourhoods being interviewed. A number of findings emerged: the young people participated in a breadth of activities and it was felt that this benefitted the needs of both the local community and the youth population; those interviewed highlighted positive outcomes of having a youth council, such as influencing policy. Nevertheless, the need to engage a broader range of young people was raised as an area for further consideration. Collins et al (2016: 140) recognised the potential advantages of youth councils, but commented that they *"remain limited in practice and the research base is underdeveloped"*.

### **The NHS England Youth Forum [NHSEYF]**

The NHSEYF was established in 2014. It now comprises twenty-five members (aged 13-25 years) from across England. The young people are encouraged to express their views about a range of health issues and to be involved in decision-making. The Forum works closely with NHS England, Public Health England as well as the Department of Health – this facilitates the hearing of the youth 'voice'. The day-to-day management of the NHSEYF has been devolved to the British Youth Council [BYC]. Further details about the NHSEYF and their work can be found at: <https://www.england.nhs.uk/participation/get-involved/how/forums/nhs-youth-forum/>

### **Research aim**

*To examine the role of the NHSEYF members and the strategies used to influence health service provision for children and young people.*

### **Methods**

A mixed methods approach was used to enable different perspectives to be appreciated (Moule and Goodman, 2014). Greene et al (1989) suggested that there are five key reasons for the use of mixed methods (initiation, expansion, triangulation,

complementarity and development) – complementarity and development were drawn on for this study, thus increasing the richness and depth of the data collection.

An Activity Log, a form of questionnaire (Figure 1), was designed following consultation with the NHSEYF membership at one of their residential weekends in June 2015; the Logs gathered quantitative data about the activities that the NHSEYF members undertook as part of their NHSEYF role.

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**An examination of the work of the NHS England Youth Forum  
Activity Log, for the period: 1<sup>st</sup> - 31<sup>st</sup> October 2015**

**Name:**..... **Age:**.....

**Gender** (please tick)                      Male                      [ ]                      Female                      [ ]

**Home** (please specify your town/village and area in England): .....

**Day to day activity** (for example, school/college/University/work/volunteer): .....

**Membership of other organisations or Youth Forums** (for example, Youth Parliament - please name):  
.....

NHS England Youth Forum activity (please describe)	In what capacity are you doing this activity?	Date(s)	Length of time	Venue	Cost

**Figure 1: The Activity Log**

Narrative inquiry informed the qualitative data collection that was undertaken via semi-structured interviews; this interpretive methodological approach enables the personal and human dimensions to be captured; in addition, it takes into account the relationship between the individual experience and the cultural context (Clandinin and Connelly, 2000).

### **Recruiting the participants**

Purposive sampling was employed as it allows for specific predefined criteria and the selection of information-rich participants (Palinkas et al, 2015). The participants sought were the twenty-five members of the NHSEYF.

### **Data collection**

Following the receipt of ethical approval, an Information Sheet was sent by a BYC employee to all of the NHSEYF members inviting them to complete Activity Logs for a three month period (October-December 2015). The NHSEYF young people received monthly emails from the BYC employee inviting them to complete the Activity Log for that calendar month. Logs, documenting activities undertaken (as well as the length of time, location and cost) were completed by nine members and returned to the research team.

Information about the interviews was also distributed (by the same BYC employee) to all members of the NHSEYF; a mutually convenient date, time and location for each interview was negotiated with the young people who wished to participate. Eight interviews took place between June-August 2016 and lasted for between 17-45 minutes; in order to maintain consistency, one research team member conducted all of the interviews. The young people gave written consent for their interview and verbally agreed to it being recorded.

### **Ethical approval**

Ethical approval was granted by the University of Hertfordshire [protocol numbers: HSK/SF/UH/00119; HSK/SF/UH/02383].

### **Analysis of data**

Descriptive statistics were used to analyse the quantitative data from the Activity Logs.

Cresswell (2012) offered the six stage 'bottom-up' Qualitative Process of Data Analysis framework; this was applied to the interview transcripts. Analysis involved first listening to the interview recordings and then reading the transcripts several times; coding was used to facilitate the emergence of seven key themes.

## **Findings**

### **Activity Logs**

Activity Logs, that fulfilled the ethical criteria, were completed by nine (36%) of the NHSEYF members (15-22 years of age). 44%(n=4) of the respondents were male and 56% (n=5) were female; 77%(n=7) were still in education; four had other additional roles and responsibilities, either paid (22%; n=2) or volunteer (22%; n=2). Six respondents were involved in other organisations as well as the NHSEYF including: Hospital committees, UK Youth Parliament; the Council for Disabled Children.

The respondents undertook a total of sixty-one activities during the three month data collection timeframe (Figure 2). Most activities took between one to three hours. Those that were less than an hour were all concerned with telephone calls and/or email communication. 45% of activities took place in the home environment, other settings included: Youth centres, public places, conferences, residential or educational locations. The total cost of all of the activities was £598.00; those undertaken at home were listed as not costing anything (young people did not claim any expenses for, for example, computer or telephone usage). Costs of over £100 were for conference attendance; the activities that were less than £100.00 were related to travel expenses.

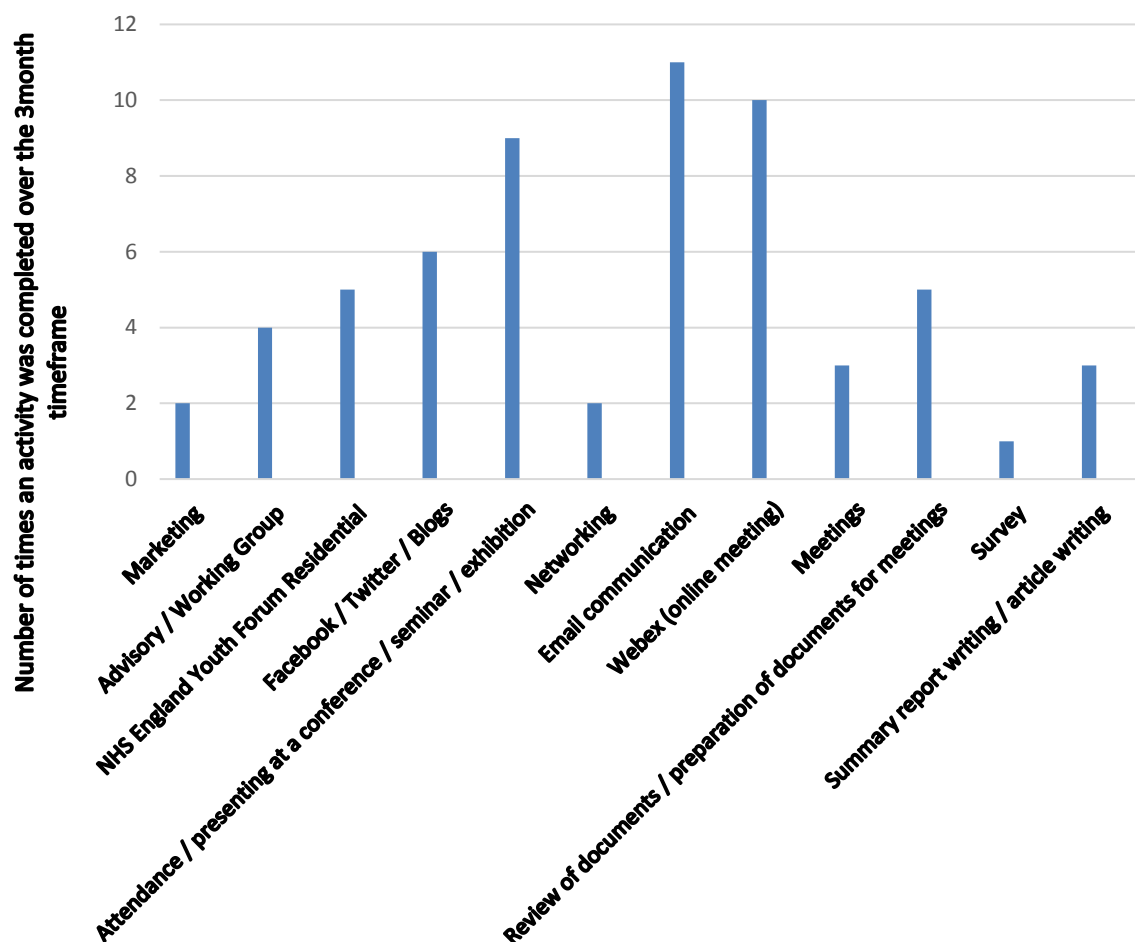


Figure 2: Summary of respondents' activities

## Interviews

Seven themes (participants' words indicate the focus of each one) emerged from the interviews that were undertaken with eight young people (four male and four female); two interviewees had been members of the NHSEYF for twenty-four months and the other six for twelve months. One young person participated in the Activity Log data collection and was also involved in an interview. The themes are presented below with discussions being supported by quotations taken from the participants' transcripts.

### Theme: ***"We want to make an impact": The young people***

The young people commented on how *"robust"* [Millie] the selection and recruitment process had been to become a member of the NHSEYF; there was also agreement that the forum included male and female young people from a range of ethnicities, backgrounds and locations. It was evident that the participants very much enjoyed being part of the NHSEYF; they demonstrated an enthusiastic approach to the work:

*“I love it so much....it amazes me, the sheer amount of work in the services and everything that goes into patient care.” [Matt]*

*“It’s getting young people’s voices across, but then for me I think the most key point is showing adults that young people want to have their voices heard and they’re not just these kids who you can put in a children’s ward and forget about.” [Alastair]*

The NHSEYF members participated in a wide range of initiatives and they thought that there was evidence of the NHSEYF’s success:

*“We got everyone on Twitter to say what it is that they want. We don’t just want it to be about the things that we believe are important. And the hashtag, the DearNHS, made for our campaign, was a letter where we actually wrote to the NHS about transitioning and about young carers in our campaign. So that led to board members hearing about it - you can imagine, we had a pretty big impact. [Chloe]*

The participants said that they had benefited from their NHSEYF membership; they spoke about their own personal development as well as their enhanced communication skills and self-confidence:

*“It’s improved my confidence level.” [Usman]*

*“I really developed team working skills, public speaking skills, you know, just confidence in general.” [Chloe]*

**Theme: “The reasons behind why I wanted to join”: Motivation**

The motivation of the members to be part of the NHSEYF was primarily related to personal experiences that had led to an interest in health issues:

*“I’ve been managing my own health and wellbeing....People with long-term health conditions....we’ve had a lot of healthcare experience.” [Chloe]*

However, the young people had become members of the NHSEYF for a range of other reasons; some had seen it advertised; others had had it pointed out to them by a colleague or friend. A minority of the members felt that the NHSEYF could assist with their career goals and/or University applications (nevertheless, this was never the only rationale given for joining the Forum). Perhaps most importantly, motivation stemmed from a desire to enable the voice of young people to be heard:

*“Young people’s voices are heard in the NHS but they’re not heard well enough.....I think what’s absolutely testament to NHS England and to BYC is that they found young people who they know are going to be dedicated and they’re going to work hard....And they are going to fight for the voices of young people and....And I think that’s great, I really do.” [Matt]*

*“It’s about young people’s voices, making an influence and making a change, improving services.” [Usman]*

**Theme: “You can’t just say ‘Oh, actually I’m busy’”: Commitment**

The participants demonstrated a strong commitment to the NHSEYF. The Activity Logs had indicated that the time spent undertaking NHSEYF work varied from week to week – the interviews supported this finding:

*“There’s no pressure to do everything. It’s just like when you have time.” [Millie]*

*“It varies throughout the week....these past three weeks I’ve had so I haven’t even checked my e-mails these few weeks. But the best thing about NHS Youth Forum is that you’re never forgotten about, you’re never cut off. They know that you’re busy, we’ve got our lives, but....I’m still part of the team.” [Alastair]*

The young people discussed the travel that was needed as part of their NHSEYF role – this included transport to the residential weekends as well key events across England. The travel requirements could be time consuming, meaning that they could not always attend activities.

It was agreed that it was beneficial to be an NHSEYF member for two years as this not only facilitated an insight and understanding of the NHS, but also provided more opportunities to be involved in initiatives (this was particularly important for those undertaking GCSE/A-Level examinations).

**Theme: “You’re working with a bunch of people that actually are all likeminded”: Community**

A key aspect of the young people’s role as a NHSEYF member involved working and collaborating with a range of personnel, this could be at a national or a local level. The participants had an excellent insight into the needs of their local youth community, much of which had arisen from growing up in the locality and accessing services. As



a result, professional relationships had been formed with key people (such as health professionals, leaders of support groups and councillors). For example, Usman explained how his local knowledge had helped him to liaise with a GP practice to highlight health issues relating to young people (specifically, teenage cancer and mental health). Chloe described her involvement with her local CAMHS [child and adolescent mental health services] support group and how she had been involved with the making of a film focussing on the transition of young people to adult services.

All of the members had participated in locally-based projects; as a result, there was a bi-directional dissemination of the work being undertaken - sometimes the young people would share the initiatives they'd been involved in locally at the residential weekends (Chloe's film was an example of this); on other occasions, the national, more strategic NHSEYF activities were taken back to the young people's home locality:

*"We're all working locally but everything contributes to the national picture."*  
[Josh]

This theme also encompassed the 'community spirit' that was fostered via the NHSEYF; the young people spoke of their commitment to common goals and the resulting friendships that had been formed:

*"It's good to have a network of friends that want similar things as you do."*  
[Chloe]

The collegiality and friendships enabled the young people to work together on key initiatives, for example, the design and production of posters and booklets relating to youth rights within a health context (NHS England, 2016).

**Theme:      "*They've got the NHS knowledge*": Knowledge experts**

The participants highlighted the important role of the NHS England employees; these people had not only been pivotal to the instigation and implementation of the NHSEYF, but they also had expert knowledge of the NHS – this provided the members with a much needed insight into the structure, organisation and policies associated with NHS England:

*“You’re actually learning a lot more about the structure and the framework of the NHS and how things operate and....it’s very rewarding that professionals are listening to you and you can have those mutual conversations even though you’re at completely different age levels. You know, that doesn’t matter, you’re still listened to and valued.” [Georgia]*

The knowledge and insight that the NHS employees were able to impart to the young people meant that their confidence grew:

*“I think it’s essential to have people from the NHS working with us, they give us knowledge and confidence.” [Charlotte]*

The participants highlighted the facilitative approach that was nurtured by the NHS employees; this in turn enabled the forming of a professional partnership approach that had the common aim of listening to the youth voice.

**Theme: “They’ve supported me”: Youth workers**

The NHSEYF members all discussed the guidance, advice and support that had been given by the BYC youth workers. Their role focussed on the daily management of the NHSEYF with communication being central to it. A range of different approaches were drawn on, this included e-mail, telephone as well as face to face discussions. Despite this, the main and most popular communication methods were the *Wednesday Weekly* (an electronic newsletter) and the closed Facebook page; these were used to provide details of forthcoming events as well as to ask the members for their opinions.

The participants were extremely positive about the youth workers and the support that they provided; the members had all developed a good rapport with them, meaning that they felt able to ask questions or share any anxieties or worries:

*“You want to do something you just ring them up, you call them and they will give you advice, they will tell you which way to go.” [Josh]*

*“The fantastic experience that you get from them....It is absolutely fantastic and their youth work, their capabilities and knowledge comes into this. It really works really, really well.” [Matt]*

### **Theme: “All my expenses are paid”: Funding**

The young people were aware that funding was required to underpin the running of NHSEYF; however, they did not demonstrate understanding of the details of this. The participants had not had any challenges in terms of claiming travel costs, but Alastair did mention that he thought that it would be “*a bit expensive*” to stay overnight so he tried to go to events that were manageable within a day.

In relation to payment for their time, there was absolute agreement by the young people that this was not required:

*“It’s for the better of young people, so I don’t want to be paid.”* [Alastair]

The interview data demonstrated that the NHSEYF members were extremely motivated and committed to their role and to enabling that the voice of young people to be heard.

### **Discussion**

One of the key findings from Matthews (2001) and Collins et al (2016) revealed that the needs of local communities were being met via the work of youth councils; this research totally concurs with this, but the national nature of the NHSEYF has meant that the positive impact has also been strategic and broader – for example, the booklet and posters reflecting youth rights in health care (NHS England, 2016) have been widely distributed to professionals across England. The tokenism, lack of authority and full representation of young people’s views highlighted by Matthews (2001) was certainly not something that emerged from the NHSEYF members; the positivity of the young people may have been facilitated (at least in part) by the knowledge experts and youth workers who they felt were totally committed to enabling youth voice to be heard. This study highlighted the diversity of the NHSEYF members, something that both Matthews (2001) and Collins et al (2016) had identified as not been evident in their research.

Many of the participants in this study had been involved in other volunteer initiatives in their local community (some of which were health related); this work had prompted several of the young people to apply to join the NHSEYF. As a result, the members

had previous knowledge of volunteering and recognised the need for a committed and motivated approach. In addition, it meant that there was a two-way dissemination of the NHSEYF work that they were undertaking with national initiatives being applied at a local level and vice versa.

Shantz et al (2013: 671) commented on the “internal ‘push’” that underpins volunteering; they suggested that organisations should facilitate the development of strong and positive relationships between both the volunteers and the recipients of their work – the volunteers are then able to see the impact of their commitment and are then likely to be motivated to undertake more activities. This was very much the case with the NHSEYF; members commented on their common goals and the friendships that they had formed. In addition, they spoke enthusiastically about the initiatives that they had been involved in and the impact that they had had. However, it is also important to acknowledge the funding required to support a youth forum as this is a fundamental resource; finances are inevitably required, this may not just include the cost of venue hire, refreshments, travel, but can also mean that there are expenses associated with the implementation of initiatives as well as staff time. The members of the NHSEYF had any expenses (such as travel, food and accommodation) paid, but none of them wanted any personal remuneration for their time commitment – this was given freely, willingly and with enthusiasm.

According to Ballard (2014), motivation can be categorised into four areas - *personal issue or cause* captures issues that the individual young person is passionate about; *beliefs* suggests that motivation stems from a specific belief about the cause; thirdly, *self-goals* relates to self-development and enhancement and finally, *response to an invitation*. This was certainly true with the NHSEYF; the young people expressed how much they had enjoyed their membership. Their participation had facilitated their personal growth and led to the meeting of local and national objectives. In addition, whilst there were many reasons why the young people joined the NHSEYF (for example, it sometimes stemmed from personal healthcare experiences; in other instances, it was thought to facilitate future career or University aspirations), motivation always came from the need to ensure that young people’s voices were listened to.

## **Limitations**

- Nine (36%) of the NHSEYF members completed Activity Logs. Whilst it is recognised that the response rate was low, the data remains valuable and may be no different to that obtained from a higher return rate (Keeter et al, 2006). Strategies (such as email reminders) were used to try to enhance the number of completed Logs (as suggested by Nulty, 2008). It is also acknowledged that self-reporting can be associated with response bias (Polit and Beck, 2011) and that information in the Activity Logs may not have been wholly accurate.
- The sample did not include all of the NHSEYF young people; it is therefore acknowledged that the findings may not be wholly representative of all of the members.
- Just one person who completed an Activity Log was also involved in a semi-structured interview; nevertheless, it is important to acknowledge that some data was obtained from 16 of the 25 NHSEYF members - it may mean that the young people were willing to engage with one method, but not another.

## **Suggestions for future work**

- Research involving health professionals to gain insight into their understanding of the NHSEYF and how its work may influence their practice.
- Consideration of how the NHSEYF could embrace the wider children and young people's community.

## **Conclusion**

This research was the first to formally evaluate a national youth forum in England. Aspects of the findings concur with some existing literature that relates to youth participation; however, new insights are offered – most notably, the key composite areas that support a successful youth forum (the young people themselves, their motivation and commitment, their familiarity with their local community [as well as their community spirit], the knowledge experts, youth workers and funding).

Whilst the Care Quality Commission (2017) survey, that was undertaken across 132 acute NHS Trusts, reported some very positive findings in relation to the experiences of children and young people, areas for improvement were highlighted (for example, 36% of children aged 8-11 years, said that they did not always understand the information given to them by staff) - the number of youth forums are continuing to grow and are undoubtedly able to play a key role in representing the views of children and

young people as well as the enhancement of health service provision. The findings from this study may be able to provide insight to others who are establishing or facilitating a youth forum within a health context.

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