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The Organisation and Provision of Youth Work Services Targeted at Young People with Long-Term Physical or Mental Health Conditions in the United Kingdom: A Service Mapping Study

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ABSTRACT

Background

Increasing numbers of young people are living with long-term health conditions and there is evidence that they experience poorer psycho-social and educational outcomes than their healthy peers. The years between 11 and 25 can be a time of sub-optimal self-management, service disengagement and deteriorating health outcomes. However, services can struggle to provide appropriate support to ameliorate this situation. In the UK, youth workers have been introduced into healthcare and other settings to improve the support of young people with long-term health conditions but there is a lack of information about these services and their role with this group of young people. This study aimed to address this knowledge gap by describing the characteristics of youth work services targeted at young people with long-term physical and/or mental health conditions.

Methods

Data about service characteristics were collected using a cross-sectional, online survey distributed via key organisations, networks and social media. This was supplemented by online searching to identify additional services. The data were analysed descriptively using SPSS.

Results

In total, 188 services met the eligibility criteria and were included in the analysis. There appears to be considerable variation in services in terms of their organisation, funding, size, and the specific groups of young people they support. Most services were targeted at young people who experience a physical health condition with far fewer targeted at young people who experience mental health difficulties. A small number of youth work services worked across physical and mental health services. Youth worker roles included emotional support, self-management support, service transition support, and advocacy. Services worked in a range of settings including hospitals, communities and schools/colleges.

Conclusion

This study contributes to knowledge by describing the characteristics of youth work services for young people with long-term physical and/or mental health conditions. Further research is now needed to understand how these services (and their characteristics) influence young people’s engagement and wellbeing and

how youth work services work with the multi-disciplinary team and wider service system.

Keywords (3-10)
Service mapping, children, young people, long-term health conditions, mental health, youth work.

INTRODUCTION

The number of young people with a long-term health condition is growing[1-3] and the increasing numbers of young people experiencing mental health difficulties is a major public health concern nationally and internationally[4,5]. Approximately 23% of 11–15-year-olds and 34% of 16-24 years olds in the United Kingdom (UK) have a long-term physical or mental health condition[6] and reports suggest that at least 25% of young people with a physical long-term health condition also experience mental health problems[7]. Consequently, there has been a significant increase in the demand for mental health services, with referrals to Child and Adolescent Mental Health Services (CAMHS) tripling between 2016 and 2024[8]. However, services have not kept pace with this increasing demand, and many young people face long waits to access mental health services[8,9]. Improving young people's access to mental health services has been a government policy goal for over decade[10-16], with a range of initiatives being introduced to expand access to support. These include the development of Mental Health Support Teams in schools/colleges; the introduction of waiting time standards; increases in the mental health workforce and the development of multi-disciplinary, open-access services (for example, Young Futures Hubs; Early Support Hubs; Youth Information, Advice and Counselling Services (YIACS))[10-16]. However, the increased demand for mental health support coupled with a lack of progress in developing preventative and early intervention support has impeded improvements being made in service access[17].

It is well established that young people with long-term conditions can experience poorer psycho-social and educational outcomes than their healthy peers and are at an increased risk of engaging in risky behaviours[18-26]. The years between 11 and 25 are a time when young people experience a range of significant emotional and social changes as they transition into adulthood and transfer to adult services [27]. For young people with long-term conditions this life-stage is recognised as a time of sub-optimal self-management, service disengagement and deteriorating health outcomes[28-30]. However, services find it difficult to provide the support

young people want and need at this stage[31,32]. Young people experience them as having an overly clinical and non-holistic approach[33]. They can feel uninvolved in decision-making and lack trust in healthcare professionals, with poor communication leading to missed appointments and poorer clinical outcomes[33-35]. Furthermore, many healthcare professionals feel inadequately prepared to support young people and find communicating with them challenging[34].

In response to this problem, youth workers have been introduced in increasing numbers into UK services to support young people with long-term health conditions[36,37]. The reasoning behind this is the belief that a youth work approach has the potential to play a key role in improving service engagement and promoting young people's confidence in living with their long-term condition thus improving their health and wellbeing[36]. The youth work approach is characterised as being informal, holistic, flexible and individualised; focussed on engagement, empowerment and advocacy; and built on a trusting, non-hierarchical relationship[36, 38-41]. Particular emphasis is placed on youth workers supporting and facilitating the holistic development of young people and on youth work's voluntary and open-ended nature[42].

However, there has been a lack of research, particularly in the UK, about youth work services that are targeted at young people experiencing long-term physical or mental health conditions. This paper reports the first stage of a larger study that aims to fill this research gap and explore how youth work services for young people with long-term physical and/or mental health conditions in the UK are organised, provided and experienced. This first stage of the study aimed to describe the characteristics of UK youth work services targeted at this group of young people and identify variation in their organisation and delivery. In the next stage of the study, we will purposefully sample six contrasting youth work services (case studies) using the service map developed from the survey as a sampling framework. The aims of this stage of the study are to examine in-depth how services are organised, delivered and integrated with the wider service system; how they influence young people's wellbeing and their engagement with services; and how they are experienced by different stakeholder groups. At each case study site, we will conduct interviews with young people and parents who have used the service. We will also interview service providers, managers and commissioners in the local service system and observe a range of youth work activities. The data will be analysed to co-develop a service development framework to guide the

commissioning, organisation and delivery of youth work services for young people living with long-term health conditions.

METHODS

Service mapping is increasingly being used to understand the 'real-life' organisation and provision of services for different groups in the population[43-48]. The approach used in this study was based on our previously conducted service mapping studies[49-52] and informed by the method developed by Price et al.[53].

Our young people's advisory group (YPAG) and our study advisory group (comprised of stakeholders from a range of organisations from across the UK) were involved in designing the mapping survey, with the latter group also supporting the distribution of the survey across their networks.

Defining the target service

A set of inclusion criteria were developed to define the youth work services that would be included in the study (Table 1).

Table 1: Inclusion criteria

	Inclusion criteria	**Exclusion criteria**
Target Population for Service	• Young people aged 11-25 with long-term physical and/or mental health conditions	• Young people under 11 years and over 25 years
Youth Work Service	• Services provided by the NHS, local government, educational organisations, Third Sector[1] organisations. • Services delivered as part of a pilot. • Service live at the point of data collection. • Service provided within/across the UK.	• Services not targeted at young people aged 11-25 with a long-term physical and/or mental health condition

[1] These are non-governmental, non-profit organisations such as charities, social enterprises, community groups.

Survey Development

The main method of data collection was an online survey using Qualtrics (Qualtrics, Provo, UT) (Supplementary File 1). It was designed to be completed by youth workers or service managers and to provide data on their service's

organisation and delivery. The survey was co-developed with our YPAG and study advisory group.

Co-production methods with our YPAG were guided by Lundy's model of participation[54]. To ensure voice, space, influence and audience were appropriately facilitated, all sessions were led by the project's participation lead (a senior youth worker) and a member of the research team. The session was also supported by a young person consultant with lived experience of a long-term condition. To meaningfully involve the young people in designing the survey, we organised a one-day, face-to-face session, attended by seven of our 10 YPAG members. The session commenced with training about survey research methods and questionnaire design before moving on to examine the draft survey in detail. The group suggested four additional questions for the survey (Supplementary File 2). These were all added to the survey apart from one as it was felt that this area could be better investigated in the case study stage of the study.

Following the co-production session with the YPAG, the study advisory group were asked to review the survey prior to a two-hour online meeting with the research team. They suggested three additional questions, one of which was subsequently added to the survey, and they also made a number of suggestions regarding the question response options (adding additional options or improving the terminology used) (Supplementary File 2). Both our YPAG and study advisory group also provided feedback on the participant information that accompanied the survey. After the amendments were made the survey was piloted and then refined before distribution.

Survey Distribution

Members of the research team and study advisory group identified both potential respondents and organisations, networks and email distribution lists who were requested to distribute an email containing information about the study with a link to the survey. Recipients were also asked to forward the email to their own relevant networks or contacts across the UK. In addition, the online survey was widely publicised through the study's social media accounts and those of other organisations. The survey was distributed between January and April 2025 and remained open until May 2025. Potential respondents were able to request a hard copy version of the survey or to complete the survey with a researcher.

Online Searches

The distribution of the online survey was supplemented by systematic online searches to identify additional services across the UK, particularly in geographical areas where there were no or few responses from the online survey. We used a range of terms for 'youth work', 'long term condition' and 'health' in Google and also searched social media sites to identify additional services. Data about these services were extracted from their websites and directly entered into Qualtrics. Services were contacted by telephone or email to obtain additional information.

Data analysis

After closure of the online survey, data were downloaded from Qualtrics in a Microsoft Excel document. The data were then cleaned and any duplicate services merged. All services were checked against the inclusion criteria (Table 1) by four members of the research team and categorised as 'included', 'excluded' or 'further information needed' if it was unclear if the service met the inclusion criteria. Services categorised as 'further information needed' were then contacted by telephone and/or email prior to a final categorisation. The final Excel spreadsheet was then imported into SPSS Statistics 28 (IBM Corp., Armonk NY) and variable names created to reflect the survey questions. The data were analysed to produce descriptive statistics (frequencies/cross tabulations). As there was a significant amount of missing data for services identified from online searches, some results relate only to a proportion of the 188 identified services. Where this is the case, the number of services providing data is specified.

RESULTS

The survey identified 290 services, of which 92 met the inclusion criteria (Table 1). Reasons for exclusion included: the service did not provide youth work services to young people with long-term conditions (n=73), the response was blank or questions about the characteristics of the service were not completed (n=104) or the response was a duplicate entry (n=21). An additional 96 services were identified from online searches. In total, 188 services were included in the analysis.

Service Settings

The large majority of services were based in England (142, 75.5%, n=188) (Table 2).

Table 2: Country of Service Base (n=188)

UK Country	Number	Percentage
England	142	75.5
Scotland	19	10.1
Wales	14	7.5
Northern Ireland	13	7.0

Most services worked in urban areas (cities or towns) with fewer services operating in rural areas or online (Table 3). No service was an exclusively online service. Many services (84, 46.7%, n=180) operated across different geographical settings (for example, city and town, town and rural area).

Table 3: Geographical Settings of Services (n=180)

Setting	Number	Percentage
City	139	77.2
Town	96	53.3
Rural	50	27.8
Online	46	25.7

Multiple responses possible

Service Funding and Organisation

The National Health Service (NHS) was the main service provider with 79 (42.2%, n=187) services, followed by third sector organisations who provided 52 (27.8%, n=187) services. A further 49 services (26.2%, n=187) were jointly provided by a statutory[1] and a third sector organisation. A small number of services were solely provided by a local government (6, 3.2%, n=187) or by an education organisation (1, 0.5%, n=187).

In terms of how services were funded, the most common funding source identified was the third sector (64, 45.1%, n=142), with the NHS funding 39 (27.5%, n=142) services (Table 4). It is notable that 30 (21.1%, n=142) services were jointly funded by the statutory and third sector (Table 4). Overall, therefore the third sector is funding 94 services (66.2%, n=142) either as single or joint funders.

Table 4: Funding of Youth Work Services (n=142)

Funding Organisation	Number	Percentage
Third Sector	64	45.1
NHS	39	27.5
Joint Funded (Statutory/Third Sector)	30	20.1
Other Statutory Service	9	6.3

[1] Public services provided by central and local government, e.g. NHS, schools.

Service Focus

The majority of services (119, 66.1%, n=180) primarily support young people who experience a physical health condition (Table 5). Less than a fifth of services (34, 18.9%, n=180) primarily support young people who experience a mental health condition; three of which were services for young people in crisis. Twenty-seven services (15%, n=180) supported both groups of young people and worked across hospital-based physical and mental health services (e.g., general children's wards, inpatient mental health units, Emergency Department (ED) crisis services).

Table 5: Primary Focus of the Service (n=180)

Primary Focus	Number	Percentage
Physical health conditions	119	66.1
Mental health conditions	34	18.9
Both Physical and Mental Health Conditions	27	15.0

There were some variations in how the three 'types' of services were funded and provided (Table 6). Over half of the physical health focussed services (51, 54.3%, n=94) were funded solely by the third sector; a larger proportion than that of mental health focussed services (7, 30.4%, n=23) or 'joint' services (6, 24%, n=25). Some mental health focussed services were funded and provided by local government and educational organisations (Table 6). Three services that focussed on both young people with physical and mental health conditions were provided by local government organisations. Across all service 'types' there is evidence of services being jointly funded and provided by different organisations across sectors.

Table 6: Service Focus and Service Funder and Provider Organisations

Organisation	Mental Health Focus Services	Physical Health Focus Services	Joint Mental & Physical Health Services
Third sector	7, 30.4% (n=23)	51, 54.3%, (n=94)	6, 24%, (n=25)

Funder	*NHS*	7, 30.4%, (n=23)	22, 23.4%, (n=94)	10, 40%, (n=25)
	Multiple[2]	5, 21.7% (n=23)	21, 22.3%, (n=94)	7, 28%, (n=25)
	Local Government	2, 8.7%, (n=23)	0, 0.0%, (n=94)	2, 8.0%, (n=25)
	Education	2 %, 8.7% (n=23)	0, 0.0%, (n=94)	0, 0.0%, (n=25)
	Third sector	12, 35.3%, (n=34)	33, 28.0%, (n=118)	7, 25.9%, (n=27)
Provider	*NHS*	12, 35.3%, (n=34)	51, 43.2%, (n=118)	8, 29.6%, (n=27)
	Multiple	6, 17.6%, (n=34)	34, 28.8%, (n=118)	9, 33.3%, (n=27)
	Local Government	3, 8.8%, (n=34)	0, 0.0%, (n=118)	3, 11.1%, (n=27)
	Education	1, 2.9%, (n=34)	0, 0.0%, (n=118)	0, 0.0%, (n=27)

[2]These were a range of different configurations of statutory and third sector organisations.

Approximately half of the youth work services (91, 48.4%, n = 188) were targeted at young people with specific health conditions (Table 7). Apart from one service, these were all services that focussed on young people with physical health conditions. The one mental health focussed specialist service provided support specifically for neurodivergent young people. The most frequently identified specialist services were those focussing on young people with cancer or palliative care needs (38, 41.8%, n=91), diabetes (13, 14.3%, n=91), or rheumatic/musculoskeletal conditions (10, 11.0%, n=91).

Table 7: Specific Health Conditions Supported (n=91)

Specific health condition	**Number**	**Percentage**
Cancer and palliative care	38	41.8
Diabetes	13	14.3
Rheumatic and musculoskeletal conditions	10	11.0
Chronic kidney disease	5	5.5
Congenital heart disease	5	5.5
Neurological conditions / epilepsy	3	3.3
Multiple specific conditions supported	8	8.8
Other (e.g. cystic fibrosis, HIV)	9	9.9

Two thirds of the services provided support to young people aged between 11 and 25 years old (110, 66.7%, n=165). Others restricted their services to those aged 11-18 (41, 24.8%, n=165) or to those aged between 18 and 25 years old (14, 8.5%, n=165). The majority of youth work services provided by the NHS worked across both children's and adult services (86, 63.2%, n=136).

Service Length of Operation

Almost half of the services (54, 47%, n=115) had been operating for six years or more. However, one third of services (39, 33.9, n=115) had been operating for two years or less, with a further 22 services (19.1%, n=115) operating for between three and five years. Only a small number of mental health focussed services had been operating for two years or less (3, 14.3%, n=21), compared to half the joint physical and mental health services (12, 50%, n=24) and just over a third of the physical health focussed services. (34.3%, 24, n=70).

Forty-nine services (46.2%, n=106) reported that they were contracted for a specific period of time and therefore would be reliant on further funding being secured to sustain their current service. Over 70% of the joint physical and mental health focussed services had a fixed term contract (13, 72.8%, n=18), compared to 42% of the physical health focused services (29, n=69) and 36.8% of the mental health focussed services (7, n=19).

Twenty-six of the 43 (60.5%) services with a fixed term contract had been operating for two years or less (Table 8). The majority of services (37, 71.2%, n=52) who had secured long-term funding were those who had been established for six years or more (Table 8).

Table 8: Service Duration and Contract Length (n=96)

Presence of a Fixed Term Contract	**Length of Service Operation (years)**			**Total**
	0-2 years	*3-5 years*	*6 plus years*	
Yes	26 (21.7%)	8 (8.3%)	9 (9.4%)	43 (44.8%)
No	7 (7.3%)	8 (8.3%)	37 (38.5%)	52 (54.2%)
Don’t Know	0	0	1 (2.1%)	1 (1%)
Total Length of Service Operation	33 (34.4%)	16 (16.7%)	47 (49%)	96 (100%)

Service Size and Qualifications

The size of the services varied in relation to the number of full-time and part-time youth workers employed (Table 9). While the majority of services were single youth worker services (75, 51%, n=147), there were 17 services that employed more than eight youth workers. The majority of single youth worker services

focussed on young people with long-term physical health conditions (67, 89.3%, n=75), whereas there were only two single youth worker services that focussed on young people with mental health conditions (2.67%, n=75) and six single youth worker services that focussed on both physical and mental conditions (8%, n=75).

Table 9: Size of Service (Number of Full and Part-time Youth Workers) (n=147)

Service Size	Number	Percentage
One Youth Worker	75	51.0
Two to Four Youth Workers	37	25.2
Five to Seven Youth Workers	18	12.2
Eight or more Youth Workers	17	11.6

Most services (64, 72.7%, n=88) employed at least one youth worker with a youth work qualification recognised by the Joint Negotiating Committee for Youth and Community Workers (JNC) (the body that sets the national framework used to grade and pay youth work jobs in the UK). At the time of the survey, 22 services (26.5%, n=83) reported that they were supporting their staff to obtain a recognised youth work qualification. Of these 22 services, the majority (16, 72.7%, n=22) were those already with qualified youth workers.

Provision of Support

Services reported that the main ways in which young people accessed their services were referrals from child health services (86, 84.3%, n=102) or via self (66, 64.7%, n=102) or parent/carer referrals (49, 48%, n=102) (Table 10). Fewer referrals were reported to be received from mental health services (3, 2.9%, n=102) or other third sector services (2, 2.0%, n=102).

Table 10: Routes to Accessing Youth Work Services (n=102)

Access Route	Number	Percentage
Referral from child health services	86	84.3
Self-Referral	66	64.7
Referral from Parent/Carer	49	48.0
Referral from Adult health services	41	42.2
Referral from ED	32	31.4
Referral from Social care	30	29.4
Referral from School/educational establishment	26	25.5

Referral from General Practitioner (GP)	25	24.5
Referral from CAMHS/other mental health service	3	2.9
Referral from other Third sector service	2	2.0
Referral from other youth work service	2	2.0

Multiple responses possible

Over two thirds of services (60, 68.2%, n=88) reported that they were able to respond to a referral within seven days, with the remaining services responding within two weeks (18, 20.5%, n=88), four weeks (4, 4.5%, n=88) or longer than four weeks (6, 6.8%, n=88).

The most common identified reason for accessing youth work services was for mental health/wellbeing support (90, 94.7%, n=95) (Table 11). Other common reasons for referral were support for health condition self-management (34, 35.8%, n=95); peer support and promotion of social relationships (25, 26.3%, n=95); education/career development (25, 26.3%, n=95) and service transition support (22, 23.2, n=95).

Table 11: Most Common Reasons for Accessing Youth Work Services (n=95)

Reason	**Number**	**Percentage**
Mental Health & Wellbeing Support	90	94.7
Health Condition Self-Management	34	35.8
Peer Support & Social Relationships	25	26.3
Education and Career Development Support	25	26.3
Service Transition Support	22	23.2
Isolation/Loneliness	21	22.1
Diagnosis Support	9	9.5
Hospital Admission Support	9	9.5
One-to-one Support/Advocacy	9	9.5
Promoting Independence	7	7.4
Family Support	7	7.4
Inclusion and Engagement	5	5.3
Financial/Housing Support	5	5.3

Multiple responses possible

Services reported providing a range of different support and activities (Table 12). The most common forms of support were emotional health support (148, 92.3%, n=156) service signposting/navigating (121, 77.5%, n=156), self-management support (110, 70.5%, n=156), service transition support (103, 66%, n=156) and advocacy (103, 66%, n=156). The most common service activities were one-to-one support (143, 91.6%, n=156), group work (100, 64.1%, n=156), service development work (67, 43%, n=156) and organising youth forums (59, 37.8%, n=156).

Table 12: Youth Work Support and Activities (n=156)

Types of Support	Number	Percentage
Emotional health support	144	92.3
Signposting/navigating to other services	121	77.5
Health condition self-management	110	70.5
Service transition support	103	66.0
Advocacy	103	66.0
Peer support	96	61.6
Support for parents/carers	91	58.4
Sexual health and relationship support	82	52.6
Training other professionals	45	28.8
Training volunteers	41	26.3
Social prescribing	37	23.7
Mentorship of young people	33	21.1
Skills accreditation	27	17.3
Types of Activities		
Providing one-to-one targeted support	143	91.6
Providing group work	100	64.1
Conducting service development	67	43.0
Running youth forums	59	37.8
Residential trips	50	32.1
Organising youth clubs	41	26.3

Multiple responses possible

The majority of youth work services offered continuing and open-ended support to young people once they had accessed their support (83, 83%, n=100), with only a small minority reporting having a formal 'discharge' process (17, 17%, n=100).

In terms of the locations where youth work services were provided, the most frequently reported settings were hospital outpatients (76, 69.7%, n=109), community (71, 65.1%, n=109) and inpatient children's wards or specialist units (68, 62.4%, n=109) (Table 13). Just under half of respondents reported providing support in schools or colleges (53, 48.6%, n=109). Additional service locations included ED (29, 26.6%, n=109), inpatient mental health units (21, 19.3%, n=109) and non-inpatient Child and Adolescent Mental Health Service (CAMHS) settings (19, 17.4%, n=109).

Table 13: Locations of Youth Work Service Provision (n=109)

Location	Number	Percentage
Hospital Outpatients	76	69.7
Community	71	65.1
Inpatient Wards and Units	68	62.4
Schools/Colleges	53	48.6
ED	29	26.6

Inpatient Mental Health	21	19.3
CAMHS (non-inpatient)	19	17.4
Hospice	12	11.0
Primary Care/General Practice	5	4.6

Multiple responses possible

Youth work services reported working with a wide range of different services across health, social care and youth justice, with safeguarding services and schools/education being the most frequently identified (Table 14).

Table 14: Youth Work Services and Multi-Disciplinary Working (n=104)

Service	**Number**	**Percentage**
Safeguarding services	77	74.0
Schools/education	76	73.1
Physical health focussed services	70	67.3
Social work	63	60.6
NHS CAMHS	59	56.7
Crisis/Emergency Mental Health Care	48	46.2
Other mental health services	46	44.2
Sexual health services	38	36.5
Youth Justice/Police	33	31.7
End of life/hospice services	25	24.0

Multiple responses possible

DISCUSSION

This is the first study to describe the organisation, characteristics and roles of youth work services that have been developed in the UK to support young people experiencing long-term physical and/or mental health conditions. We have discovered that there appears to be considerable variation in services in terms of how they are funded, the provider organisation, their size, length of operation and the particular groups of young people they target. In terms of location, the vast majority of youth work services were based in England which reflects that England's child population is 10 times larger than the other three nations[55]. Consistent with the wider provision of youth work services, most services worked in urban areas and only a small number operated in rural areas[56] which creates inequalities in access to services. A quarter of services delivered their service online alongside in-person provision which reflects the increasing inclusion of digital youth work within services to both improve access and support in-person sessions[57,58]. The majority of services were targeted at young people who

experience a physical health condition with far fewer targeted at young people who experience mental health difficulties. A third group of services were identified who support both groups of young people and work across hospital-based physical and mental health services which is consistent with the wider development of integrated physical and mental health services for young people[17,59]. Almost half of the youth work services were focussed on young people with specific health conditions, with cancer/palliative care needs being the most frequently identified. Youth workers' roles included emotional support, service signposting/navigation, self-management support, service transition support, and advocacy. They provided this support to young people in diverse settings and worked with different services across health, education, social care and youth justice.

While traditionally youth work has been associated with working with a wide range of young people in diverse community settings, since 2000 it has been increasingly targeted at supporting socially excluded and 'at risk' young people[60]. This study has revealed how this targeting has widened to include young people with long-term health conditions, possibly as a consequence of a recognition by statutory and third sector organisations of the potential benefits of utilising the skills of youth workers to support this group of young people. Survey respondents identified that emotional support was the main type of support they provided (and the main reason for referral to their service). This finding resonates with other recent studies which have highlighted how youth workers are increasingly providing mental health support, with many reporting that this is now the main focus of their work[61]. Indeed, there is evidence that youth workers feel confident in providing mental health support[61] and that youth work's person-centred approach, based on the establishment of trusting relationships and the creation of safe spaces can have a positive influence on young people's mental health[62]. In addition, in this study youth workers were using their skills to support young people in self-managing their health condition and acting as their advocates. However, there has been a lack of research to understand this extension of the youth worker's role and how it is experienced by young people, youth workers and other practitioners and their influence on young people's health and wellbeing.

Two thirds of youth work services provided support to young people up to the age of 25 years old, with the majority of NHS provided youth work services working across both children's and adult services. This is consistent with another finding from this study that supporting young people during the transition and transfer to

adult services was one of the most frequently identified roles of youth work services. For many years there have been recommendations that young people should be allocated a key worker/transition navigator to act as a facilitator for the transition process and to plan coordinated, individualised support across health, social care and education[63-66]. There is evidence that such a worker may improve the transfer process and young peoples' self-management skills[67,68] and that they are valued by young people[63,69]. While this study suggests that youth workers are supporting young people during transition to adult services, their role during this process has not been investigated.

Self/parent referral was the most common means of accessing youth work services. There is evidence that young people and parents value being able to self-refer to services as it can overcome the access barriers they experience[70-73]. Open access and self-referral are key characteristics of services underpinned by the Youth Information, Advice and Counselling Services (YIACS) (or Youth Access) model which provide holistic, young person centred, and integrated wellbeing support for young people up to 25 years old in community settings[74]. This service model was introduced as a means of improving young people's access to mental health services and was specifically recommended in government policy[12]. There is evidence that young people value and benefit from their engagement with YIACS, with self-referral being particularly identified as an important aspect of these services[75-77].

The majority of youth work services in this study reported that they offered open-ended support to young people once they had accessed their service, with only a small minority reporting a formal 'discharge'. Previous research has found that the ability to 're-enter' a service when needed is important for young people and parents, providing a sense of security[72]. Indeed, an open-ended context is emblematic of youth work as it provides the time to develop trusting relationships with young people and provides them with choice over how and when they participate[62].

There was a wide variation in funding arrangements and the consequences of this for these services are currently unknown. It was notable that the third sector was involved in funding the majority of youth work services either solely or in combination with a statutory organisation. Although third sector funding within the statutory sector can be beneficial in terms of innovation, there are concerns that

this funding is not guided by clear policy and has the potential to widen existing inequalities[78,79]. Indeed, it has been noted that this type of funding tends to focus on particular 'causes' and on 'elite' NHS organisations[78]. In this study it was evident that a significant number of youth work services were focussed on specific physical health conditions, in particular young people with cancer or palliative care needs, which may reflect the investment in youth work services made by cancer related charities. However, this may create inequalities in the support available to young people with different health conditions and widen geographical inequalities.

While this study has revealed the characteristics of youth work services for young people with long-term health conditions, further research is now needed to understand in-depth how these services are experienced by young people, parents/carers and other service providers; their influence on young people's engagement and wellbeing; and their integration with the multi-disciplinary team and wider service system. Furthermore, it is unknown whether youth workers are able to retain their particular approach to supporting young people when they move into new settings or whether their role is shaped to conform with organisations such as the NHS.

STRENGTHS AND LIMITATIONS

The study addresses a knowledge gap about the characteristics of youth work services targeted at young people with long-term health conditions in the UK. It has provided insight into their location, organisation, funding and the support they provide. It has used robust methods with the survey being co-developed with key stakeholders to enhance survey design. The use of a comprehensive, systematic sampling approach has enabled us to capture a diverse range of services across the UK. However, although we implemented an extensive broad-based survey dissemination strategy and included snowball sampling to enhance coverage, we recognise that there may have been eligible youth work services who did not receive the survey and others who may have decided not to complete the survey which will likely have introduced selection bias. Hence the representativeness of the sample is unknown. Using online searching to identify additional services has its limitations as this will have only identified services with an online presence. Smaller services and those with a less developed website may have been missed. In addition, the information provided on websites may have been out of date. Although we contacted services identified from online searches for further information about their service, many did not respond and consequently there is

missing data for many variables. In addition, services are dynamic and therefore their data are only accurate at the time of data collection.

CONCLUSIONS

Youth workers have been introduced into UK services to support young people living with long-term health conditions with the aim of improving their service engagement and their health and wellbeing. However, there has been a lack of research about these targeted youth work services. This study has contributed to knowledge by describing the characteristics and roles of these services. We have discovered that there appears to be considerable variation in services in relation to how they are funded, organised, their size, length of operation and the particular groups of young people they support. Further research is now needed to understand the impact of these youth work services on young people's engagement and wellbeing.

List of Abbreviations

ED	Emergency Department
CAMHS	Child and Adolescent Mental Health Services
GP	General Practitioner
HIV	Human Immunodeficiency Virus
JNC	Joint Negotiating Committee for Youth and Community Workers
NHS	National Health Service
UK	United Kingdom
YIACS	Youth Information, Advice and Counselling Services
YPAG	Young People's Advisory Group

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Authors' contributions
SK, MM, NR, NB, RP, AF, MD, DH conceptualised and designed the study. SK, MM, RG, NR, NB, RP, AF, MD, DH designed the survey. RG and CF collected the data. All authors were involved in data analysis and interpretation. SK drafted the manuscript. All authors have read, commented on and/or approved the final version of the manuscript

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Availability of data and materials
The anonymised datasets used and/or analysed during the current study may be available from the corresponding author on reasonable request.

DECLARATIONS

Ethics approval and consent to participate
This study received exemption from ethical approval from the University of Manchester Research Ethics Committee. The study was conducted in accordance with the Declaration of Helsinki. Respondents provided informed consent before beginning the survey.

Consent for publication
Not applicable

Competing interests
The authors declare that they have no competing interests

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