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Exploring the potential to normalize developmentally appropriate healthcare for young people in hospitals

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Exploring the potential to normalize developmentally appropriate healthcare for young people in hospitals

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ABSTRACT

Objective The World Health Organisation has argued that adolescent-responsive health systems are required. Developmentally appropriate healthcare (DAH) for young people is one approach that could underpin this move. The aim of this study was to explore the potential for DAH to become normalized, to become a routine, taken-for-granted, element of clinical practice.

Design Qualitative ethnographic study. Analyses were based on procedures from first-generation grounded theory and theoretically informed by normalization process theory.

Setting Two tertiary and one secondary care hospital in England.

Participants 192 participants including health professionals (n=103) and managers (n= 72) were recruited. Approximately 1600 hours of non-participant observations were conducted, alongside 65 formal qualitative interviews.

Results We observed diverse values and commitments towards the care of young people and provision of DAH, including a distributed network of young person-orientated practitioners. Informal networks of trust existed, where specific people, teams or wards were understood to have the right skill-mix, or mind-set, or access to resources, to work effectively with young people. As young people move through an organisation, the preference is to direct them to other young person-orientated practitioners, so inequities in skills and experience can be self-sustaining. At two sites, initiatives around adolescent and young adult training remained mostly within these informal networks of trust. At another, through support by wider management, we observed a programme that sought to make the young people's healthcare visible across the organization, and to get people to reappraise values and commitment.

Conclusion To move towards normalization of DAH within an organisation, we cannot solely rely on informal networks and cultures of young person-orientated training, practice and mutual referral and support. Organisation-wide strategies and training are needed, to enable better integration and consistency of health services for all young people.

Strengths and limitations of this study

- This is the first ethnographic study addressing the provision of developmentally appropriate health care for young people.
- Exploring the provision of health care for young people over time, within specific teams and specialities, as well as across an organisation, enabled us to explore the diversity of ways that health care for young people is currently delivered within and across professionals, teams, wards and organisations.
- We only focused on three different organisations and all these organisations had a reputation for undertaking research on the care young people, so may represent examples of 'good practice'.

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15
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20
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31
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34 the writing of this manuscript. All authors worked on drafts of the paper and approved the final
35 version of this article.
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49 permission for data sharing.
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53 **Supplementary Files:** Original Protocol; Standards for Reporting Qualitative Research (SRQR)
54 Checklist.
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INTRODUCTION

The health of young people, defined by the World Health Organisation as any person between ages 10 and 24 years,[1] is a neglected yet pressing global issue [2] affecting the largest generation in history.[3] Youth-friendly healthcare [4], promoted as a means to improve health services for young people, has underpinned quality of care and policy frameworks.[5-7] However, as highlighted by the WHO, there is the need to move from the ad hoc provision of youth-friendly healthcare services to adolescent-responsive healthcare systems [8]. Other work has also noted that health system-level strategies are needed to further develop and improve healthcare for young people [9,10].

Healthcare providers need to respond to young people's changing developmental needs in a manner that is consistent, universal and provided across healthcare settings. Such adolescent-responsive health systems should be flexible, and should focus on a broad range of aspects of healthcare provision, from the frontline (such as how healthcare professionals communicate with young people) through to the higher levels of healthcare provision (such as how services are planned and commissioned).

Developmentally appropriate healthcare (DAH) for young people [11-13] is one concept that could underpin an adolescent-responsive healthcare system (See Table 1). In contrast to the more service-focussed nature of the youth friendly health service [14], DAH addresses the clinical approach to individual young people and specifically recognises the changing developmental needs of young people and the role of healthcare in addressing and supporting young people. DAH focuses on biopsychosocial development rather than chronological age. Chronological age is recognised to be a poor indicator of developmental status particularly in the context of a long-term health condition [15]. Young people make this journey to adulthood in their own way; young people's development does not have a fixed period attached to it. Many developmental milestones are met after reaching the legal age of adulthood [16,17].

[Table 1]

Services underpinned by DAH have been reported nationally and internationally as a potential key mechanism to improve health outcomes for young people.[3,18] Increasing knowledge about the development of young people [19,20] offers unprecedented opportunities for service improvement. In the context of sub-optimal provision of healthcare for young people,[3,8] DAH offers the potential to transform traditional models of healthcare delivery into adolescent-responsive healthcare systems. However, the concept of DAH has been operationalized in a range of ways in the medical literature [11] and is understood in different ways by clinicians and managers in the NHS[12]. In this study, theoretically informed by Normalization Process Theory (NPT)[21], we investigated the

1
2 potential for normalization of DAH within three UK hospitals. NPT identifies, characterises, and
3 explains aspects of individual and collective behaviour shown to be important in empirical studies of
4 the introduction, embedding and integration of change [21]. Normalization is achieved when a
5 technique, technology or organisational change becomes a routine and taken-for-granted element
6 of clinical practice.
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11 12 13 **METHODS**

14
15 This ethnographic study was conducted across three hospitals in England (a district general hospital,
16 a large paediatric tertiary hospital and a large adult tertiary hospital) all with a history of
17 championing research and innovative service provision for young people. Health professionals,
18 recruited through six medical and surgical specialties (Diabetes, Emergency Care, General
19 Paediatrics, Outpatients, Rheumatology, and Trauma and Orthopaedics), were chosen to represent
20 the heterogeneous services found in UK National Health Service (NHS) hospitals. Managers were
21 recruited at each site when their roles were relevant to the provision of services for young people in
22 paediatrics and/or adult care. The study received a favourable opinion from the National Research
23 Ethics Committee (12/NE/0423).
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33 Data collection took place over three phases, between June 2013 and January 2015. Recruitment
34 was initially mediated through gatekeepers. Participants were purposively sampled, initially through
35 maximum variation sampling and then refined through snowball and theoretical sampling. [22]
36 Participants were approached using a variety of methods including face-to-face, telephone and
37 email. A total of 192 participants (professionals and managers) were recruited (Table 2).
38 Approximately 1600 hours of non-participant observations were conducted by two researchers, (AF,
39 VW) alongside 65 formal qualitative interviews. Researchers had specific training and extensive
40 experience in conducting qualitative research and had no relationship with the participants.
41 Observations were recorded in contemporaneous fieldnotes. Formal interviews (average length, 45
42 minutes) were audio-recorded, transcribed, edited to ensure respondents anonymity and then
43 analysed alongside anonymised fieldnotes. Observation and interviews focused on the organisation
44 of services for young people, including (intra-/inter-)organisational, team and individual aspects of
45 provision, training and support, and patient involvement as well as emerging topics identified
46 through concurrent data analysis.
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57 **[Table 2]**
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3 All analysis was conducted according to the standard procedures of rigorous qualitative analysis by
4 AF, VW and TR.[23] We used procedures from first-generation grounded theory - coding, constant
5 comparison, memoing [24] - and from analytic induction, deviant case analysis.[25] Sampling, data
6 collection and analysis occurred concurrently, so that issues raised in earlier phases of fieldwork
7 were explored subsequently to enable conceptual saturation [26]. We undertook independent
8 coding and cross checking, team data sessions and member validation with some of the participants
9 in the fieldwork. The analysis was assisted by QSR NVivo 10 software and theoretically-informed by
10 Normalization Process Theory.[21]

11
12 This study was part of a larger longitudinal programme of research focused on the commissioning
13 and provision of healthcare services for young people [27,28]. A young people's advisory group
14 supported all studies within the programme. The group advised on practical (e.g. recruitment) and
15 conceptual issues (e.g. discussion of key findings and concepts).

26 RESULTS

27
28 We identified diverse values and commitments towards the care of young people and provision of
29 DAH across organisations, specialities and staff. We observed a range of informal cultures of good
30 practice implementing core elements of DAH, alongside formal and informal cultures of training
31 around DAH and the provision of care of young people.

36 Diverse values and commitments

37
38 When discussing the provision of care for young people, many focused on the need to create a more
39 age appropriate environment, in terms of physical space, the visual and material culture of waiting
40 room and wards. Others, especially those who worked regularly with young people, discussed
41 features such as appropriate communication, confidentiality and a more holistic focus. As one
42 manager noted:

43
44 The young people have told us that, um, we need, they're not bothered about where they
45 are seen so, as in, what the building's look like or what the clinic room looks like. They want
46 to make sure that they see somebody who's interested and who knows what their disease is
47 like, but also has an awareness of all the other stuff that's going on when they're 16 to 18
48 (Manager, General Hospital)

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50 At this hospital, involvement was considered to be part of patient experience, and young people
51 were involved in such activities as the, attendance at governance meetings and training of staff.
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3 Young people's experiences were an important influence on this manager's understanding of
4 'appropriate' service provision.
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7 There were conflicting views on the value and worth of enacting DAH across the organisations. The
8 numbers of young people accessing health services were often portrayed as small, so in
9 organisational terms they were 'just below the radar'. In contrast to older, especially elderly
10 patients, they were also seen as 'very rarely unwell'. This led some to question whether
11 professionals should be adjusting their practices or offering distinct, tailored, services, as there are
12 always competing demands for resources, time and expertise.
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18 It's small enough [numbers] that if you don't, if you don't buy into it, there's plenty to be
19 getting on with the other 90%. And everybody's jobs are so frantic that you could easily do a
20 very good job with that 90% who are 25, 26 plus. ... So, you could actually ignore these
21 young people completely. (Manager, Adult Hospital)
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25
26 Questions of legitimacy and buy-in, or rather, enrolment, are central to individual, team and
27 organisational change. In part, this lack of capacity and willingness seems to be compounded by the
28 liminal status of young people within the organisational and professional culture of the UK
29 healthcare system:
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32
33 Adults don't really want them because they are too young and the paediatricians don't really
34 want them because they are too old (Health Professional, General Hospital).
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38 With the exception of charity-supported oncology wards, adolescent only wards, or spaces within
39 wards, were rare and were often subject to dissolution if there were competing demands. None of
40 the sites had a senior clinical or management lead with responsibility for young people's service
41 development.
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45 However, across all the sites we did observe a complex network of young person-orientated
46 practitioners, people acting as young people 'enthusiasts', or 'champions', within specific clinical or
47 management teams in either a formal or informal capacity. Some specific services and practices
48 were organised around the care of young people. However, relying on the enthusiasm and
49 willingness of specific individuals can become problematic.
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56 Several people have left, who have been very senior members and very adolescent minded
57 and have been replaced by either rotational posts or part-time posts, so that continuity
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2 within our team and the wealth of expertise has been impacted on significantly. (Health
3 Professional, Paediatric Hospital).
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6 A focus on champions raises key questions about the sustainability of services for young people over
7 time.
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10 **Informal cultures of good practice**

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13 Across all three hospitals, we observed local cultures – in teams, clinics, wards and meetings – where
14 professionals attempted to enact a philosophy of care towards young people. They were driven by
15 an awareness of how approaching young people in a different way can mean that young people
16 ‘might take the right messages away, might not end up neglecting their health needs, damaging
17 themselves’ (Manager, General Hospital). For these professionals, working with young people
18 required a specific mind-set and skill-set.
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24 At its simplest level this often involved the ability of the professional, or the multi-disciplinary team,
25 to communicate effectively, listening to young people about their health needs and asking them
26 questions, about their broader psychosocial situation. Care is contextualised by gathering
27 information about a young person’s life, including educational, vocational, social, friendship and
28 family issues; and exploring risk and resilience factors. Such information is used by teams to
29 generate an appropriate context for effective communication, inform interventions and to organise
30 consultations, including offering appropriate health education and support for self-management.
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36 Providing an appropriate service for young people is often a deeply rooted value for these
37 individuals and groups. The ‘You’re Welcome Quality Criteria’ [6] were generally well known,
38 including core issues such confidentiality and consent, joined-up working, transition and
39 accessibility. Within the context of adult care, failure to attend appointments was a prevalent issue.
40 Ways of dealing with this varied and we were told about what was referred to as, ‘a softer approach
41 to the DNAs (did not attend)’
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48 The organisation ruling of one strike and you’re out, we don’t adhere to, so we will give
49 them multiple attempts to come into clinic ... we don’t actually put them as a DNA, because
50 they just booked in [the consultants] calendar but we don’t actually book it on the system so
51 they don’t officially come as a DNA ... So I’ll make informal appointments with the young
52 people and then, when they arrive we book them into clinic, so that way they don’t DNA
53 (Health Professional, Adult Hospital).
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2 Working creatively within the existing norms, rules and resources was characteristic of those who
3 believed that young people needed to be recognized as a group with specific needs and approaches.
4

5
6 We observed across all the organisations ‘lots of great pockets of work’ as some specialties, teams,
7 people or spaces offered very strong young person-orientated care. However, not all people or
8 services felt it relevant to make ‘special arrangements’, but chose instead to treat young people like
9 ‘an ordinary patient’. Alongside this, the uneven distribution of resources within and across
10 specialties can create inequities of care.
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16 There are ... areas in the hospital who, because they have more funding or they’re funded in
17 a different way, they might have a youth worker because it’s part of their team and just for
18 their team. They might have a psychologist who is just part of their team. ... it very much
19 depends on what speciality you’re unfortunate to fall into, depending on what illness you’ve
20 got as to what service you then get. ... (Health Professional, Paediatric Hospital)
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25 However, resources are not the only source of inequities. In part the inequities in skills and
26 experience across the organisations seem to be self-sustaining within organisations. Those with an
27 interest, the ‘enthusiasts’, are embedded in an informal network of care.
28
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31 we’ve now got a group of interested people across the [organisation]. So if a young person
32 comes to me and they’ve got a, a joint problem, but they’ve also got a bowel problem, I
33 know which bowel consultant and which bowel nurse will be the most appropriate to send
34 them to. ... Um, so we’ve got a good group of people across the [organisation] that we can
35 actually send these youngsters to who’ve got more awareness of the issues that they could
36 have (Health Professional, General Hospital)
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42 An informal knowledge economy of young person-orientated practitioners and practices exists
43 within the organisations. These are networks of trust. These referrals help to create, sustain and
44 reinforce the network over time. This practice also exists across organisations, especially in terms of
45 the transfer of young people to adult services. Young person-orientated practitioners refer to other
46 young person-orientated practitioners – in this way, they work to actively avoid referring young
47 people to those they feel maybe less young person-orientated. These people then gain less practical
48 experience with managing these patients, and so less chance to reappraise their values and
49 commitment to working with young people in new ways, as well as to develop the right skill-mix.
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56 An informal network also existed in terms of spaces. At each site, at least one specific ward was
57 known to offer more young person-orientated care. They were seen as repositories of knowledge
58 and skills, able to advise on or manage potentially challenging behaviour.
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3 We were getting so much enquiries regarding adolescents from the other wards, even just
4 for the basics. ... So, they would ring us and say, "We can't get them out of bed in the
5 morning". You know, "they just want to stay in bed all the time and they don't want to
6 interact with anything". So we would say, "Well then you have to be stern, you know, you
7 have to tell them, 'This is the plan,' you have to do a contract with them and agree with
8 them that if they get over this time, then they can do this at this time" (Health Professional,
9 Paediatric Hospital).

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15 It is not only that 'just different wards have a different tolerance', but rather that different wards
16 and teams, develop, over time, different understanding and a different sense of what is legitimate
17 work, as well as developmentally appropriate skills, competencies and routines.

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21 In some situations, we've had patients on our general wards where the parent has wanted
22 to stay. And we, my nurses, would find that very strange. But actually, in oncology, that
23 would not be strange at all. Because ... [they] would be used to that, even a patient could be
24 22, 23 and still may want their mum. But they're not exposed to that in the main wards.
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27
28 (Health Professional, Adult Hospital)

29
30 Exposure to working with young people was central to enabling young people to become seen as
31 just another 'young patient', over a set of unknown and unexpected concerns. Exposure offers a
32 chance to adjust expectations and develop new skills.

33 34 35 36 **(In)formal cultures of training**

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38
39 Within each of the organisations there were formal and informal groups at which the young person-
40 orientated enthusiasts met and supported each other collectively. Essentially, these groups were a
41 collective effort to promote initiatives to raise awareness across the organisations, create change,
42 offer support and, importantly, learn from each other outwith their team, area or specialty.

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45
46 I have nothing in writing in my job plan that says I specialise in young people. ... Nobody said,
47 "If you want to be a young adult person, you need to go on this [training course]". It's just
48 something that I became aware of through organisations or talking to people. So, it's all
49 quite ad-hoc rather than really, really planned. And it's just really by hearsay and talking to
50 people and networking throughout [this organisation] over many years. (Health Professional,
51 Paediatric Hospital)

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3 Without any formalised professional routes available, the local, regional and national special
4 interests groups became a central resource for supporting adolescent and young adult health
5 training across the organisations.
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8 At two hospitals, the only initiatives involving training around young people originated from their
9 respective special interest groups, in the form of annual study days. At one of these hospitals, there
10 was a policy initiative explicitly around transition, yet no specific training had been organised. At the
11 other, development of a formal policy was said to be 'not a priority for the organisation'.
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16 Priorities are the front door, A&E [Accident and Emergency], Clinical Decisions Unit, waiting
17 times and, it's those things that they are being judged on.
18

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20 Interviewer: Why do you think this is not a priority at all?
21

22 Just because they've got bigger fish to fry. ... But it's not a priority for the [organization]
23 because of all the other things by which they are measured. And young people's care isn't on
24 that list. (Manager, Adult Hospital)
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28 In the current context of the factors that drive organisational change at this site, creating further
29 engagement and buy-in from senior management were not seen as practical solution. Issues about
30 the care of young people remained focused in the informal, organisation-wide group, of young
31 people's enthusiasts. As we discovered, not everyone interested in the care of young people in that
32 organisation was aware of the existence of that group. Even those within the group were often
33 unaware of the range of young person-orientated initiatives that were occurring within their
34 organisation.
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41 At the remaining hospital specific training around the topic of DAH was observed being planned and
42 delivered. A DAH strategy emerged as the result of the work of key people who sat on a transition
43 strategy group. The group comprised of managers and health professionals, who met bi-monthly.
44 There was strong cross-over between managerial and clinical levels and they worked to actively
45 foster communication and create connections across services. The ideas emerged from the local
46 special interest group, but the dissemination was targeted well beyond that group. Part of this
47 involved looking where change was currently occurring within the organisation, alongside the
48 broader national agendas on young people's health, in order to harness that momentum and get
49 people involved.
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57 The focus of the strategy and training was on organisational level factors (e.g. staff appraisal
58 including training goals around young people; provision of age-banded clinics), clinic and
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3 consultation level factors (e.g. signpost sexual health, drug and alcohol services; copying clinic letters
4 to young people), and training and awareness factors (e.g. adolescent development; confidentiality).
5
6 This programme of training had senior management support, albeit initially only from child health,
7 alongside access to resources. Using money to 'back fill' was seen as a key component in the success
8 of the roll-out of training, as without this departments would not only be unwilling but also unable
9 to release staff for training.
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13 Last year we did, um, we did ten days, so ten individual day sessions for training in
14 adolescent, basic adolescent health. Basically to increase awareness across the
15 [organisation] so as to make sure it wasn't just the, the chronic illness patients that were
16 being looked at ... but it was the patients coming through A&E, coming through X-ray ... just
17 to get them aware of what a young person's needs are and why they're different to being an
18 adult (Health Professional, General Hospital).
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24 Central norms and practices of good, every day, care for young people were distributed well beyond
25 the local existing networks. The initiative emerged from, and depended on, their enthusiasm and
26 expertise. The network of trust of young person-orientated practitioners was then supported by key
27 actors within wider management. This led to an on-going training programme that sought to make
28 the young people's healthcare visible across the organization, to begin to get to people to reappraise
29 values and commitment.
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38 **DISCUSSION**

39
40 Across each organisation a complex, distributed, network of adolescent-oriented practitioners
41 understood the potential value and worth of practices and services for young people, such as DAH.
42 Within and across organisations there is an informal knowledge economy of young people-oriented
43 practitioners, teams and spaces. People have a preference for referring to other young person-
44 orientated practitioners or spaces, to others within their networks of trust. Such referrals help to
45 create, sustain and reinforce the network over time. As such we see evidence of strong
46 communities of practice [29], focused on supporting and enacting adolescent medicine. Table 3
47 illustrates our results in relation to the four theoretical constructs of normalization process theory
48 (NPT),[21]. The potential for normalization of DAH is high within the group of young person-oriented
49 practitioners and managers, as they make sense of, buy-into, enact, and evaluate it as worthwhile.
50 Beyond the networks of young person-oriented practitioners and managers, we observed a low
51 potential for normalization. There are differences in opinion about the meaning and worth of DAH,
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3 its organisational and policy relevance, its potential workability, and its resource and spatial
4 allocation. However, at one hospital, providing an organisation-wide strategy and training on
5 organisational, team, clinic and consultation level factors offered a clear opportunity to increase the
6 potential for normalization. It relied on buy-in and formal support from senior managers in both
7 child and adult services to initiate and sustain it.
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11 [Table 3]

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14 This is the first ethnographic study addressing the area of developmentally appropriate health care
15 for young people. This study gathered considerable data from many sources. The focus on exploring
16 the provision of health care for young people over time, within specific teams and specialities, as
17 well as across an organisation, enabled us to demonstrate the diversity within and across
18 professional, team, ward and organisational boundaries. However, we only focused on three
19 different organisations. Notably, all these organisations had a reputation for undertaking research
20 on the care young people, so may represent examples of 'good practice'. Given the timing of our
21 fieldwork, we did not get the opportunity to observe the impact of the roll-out of training around
22 DAH that occurred at the one of the NHS trusts.
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30 Policy and research has emphasised the centrality of service delivery and workforce capacity issues
31 to achieve successful integration and consistency of health services for all young people across
32 organisations [8, 9]. The results presented here add to this evidence base as we observed how the
33 community of practice, the networks of young person-orientated practitioners and managers also
34 support and provide, through formal and informal means, training and development around young
35 people's health. Previous research has shown that continuing medical education in adolescent
36 health, can increase developmentally appropriate practices (such as confidential services) and has
37 the potential to address systemic barriers to healthcare for young people.[30] Thus, the role of such
38 networks may be vital to achieving any sustainable change in the provision of healthcare for young
39 people. Across all the sites, young people's formal and informal champions were key to getting
40 people involved in the healthcare of young people. Research has outlined the importance of staff
41 attitudes as a key determinant of young people's satisfaction with care.[4, 31] Prior research has
42 also shown the problem of staff turnover, if services rely on key individuals [32,33] . As such, there
43 needs to be consistency of approach to developing local cultures of good practice that can withstand
44 changes in personnel. In primary care, the Adolescent Champion model, which trains a
45 multidisciplinary team of practice staff to deliver training to other staff and implement local quality
46 improvement, has shown potential for sustainable change [34].
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3 Our findings suggest that there is a need for strong and clear guidelines, strategies and policies on
4 the practical implementation of DAH at three levels: those of the individual young person and their
5 family, the multidisciplinary team level and the organisation and/or system level. Our research
6 informed the development of a freely-available online toolkit for implementation of DAH at these
7 levels.[35,36] Since the fieldwork ended, additional guidance has been published including for the
8 care of young people in acute care settings [37] which includes a focus on DAH, alongside national
9 guidance on the need to implement DAH in relation to transitional care.[18] A focus on specific
10 settings (like acute care) or contexts (like transition) has limitations as it can introduce or sustain
11 inequities. Buy-in and formal support from senior managers in both child and adult services seems
12 essential. Providing an institution-wide strategy and training seems key, particularly in view of the
13 current unmet training needs reported in both paediatric [38] and adult physicians [39]. Currently
14 adolescent and young adult medicine is not a recognised discipline in its own right in the UK unlike
15 Australia and North America [40] although even when it is an established discipline, challenges
16 remain, for example in the USA [41]. The 'informal' adolescent and young adult medicine community
17 in the UK may also need to become more formally recognised. Young people should no longer be
18 seen as 'vary rarely ill' or allowed to remain 'just below the radar', or seen as 'too old' for child
19 services or 'too young' for adult. Core principles underlying the practice of adolescent medicine,
20 such as DAH, should not remain contested. We need to enable people to reappraise values and
21 commitment, to understand them as a normal part of everyday service provision.
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3 **Table 1: The five dimensions of Developmentally appropriate healthcare (DAH)**
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5 **Dimensions of DAH for Young People** ⁹⁻¹¹
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7 **Biopsychosocial development and holistic care:** a focus on biopsychosocial development rather than
8 chronological age, with routine biopsychosocial developmental assessment and approach to the young
9 person adjusted accordingly
10

11 **Acknowledgement of young people as a distinct group:** the recognition that their specific needs - in
12 terms of informational resources, services, spaces, pathways and required competencies of staff - are
13 distinctly different to those of younger children and older adults as a result of their developmental
14 status.
15

16 **Adjustment of care as the young person develops:** the need for flexibility to acknowledge the
17 biopsychosocial developmental changes over time and the potential for regression in relapsing health
18 conditions
19

20 **Empowerment of the young person by embedding health education and health promotion:** that
21 knowledge and skills training for young people is embedded into routine clinical practice to enable them
22 to gradually become more autonomous with respect to the care of their own health as they grow up.
23 Services need to be designed so as to nurture and support such skill development.
24

25 **Interdisciplinary and Inter-organisational work:** a focus on continuity of care, coordination, consistency
26 and communication across agencies. Connecting health, education, employment, social, voluntary
27 agencies at a clinical and system level.
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Table 2 - Recruitment for the study by site, type of staff and method of data collection

		District General Hospital	Paediatric Tertiary Hospital	Adult Tertiary Hospital	Total
Participants observed	Health professionals	65	27	11	103
	Managers	57	0	15	72
	Total	122	27	26	175
Participants interviewed	Health professionals	13	18	10	41
	Managers	13	6	5	24
	Total	26	24	15	65
Overall participants	Health professionals	78	45	21	144
	Managers	70	6	20	96
	Total	148	51	41	240
Number of participants who were both interviewed and observed		39	5	4	48
Total number of participants		109	46	37	192

Table 3: The four constructs of Normalization Process Theory (NPT) mapped against practitioner groups

NPT Construct	Networks of young person-oriented practitioners and managers	Other practitioners and managers who work with young people
Coherence: Do people make sense of DAH?	See how DAH extends and is related to other approaches to care of young people; relatively shared understanding of purpose of DAH; understanding of impact of DAH on their work; and see potential value and worth of DAH	Diverse views on relationship to other approaches; lack of shared understanding of purpose of DAH; diverse understanding of potential impact of DAH on their work; uncertainty around of potential value and worth (especially, given competing demands)
Cognitive Participation: Do people get involved with providing DAH and stay committed?	They are the key people driving DAH forward; they see DAH as legitimate, generally core, part of role; are very willing to work with others to enable DAH; and motivated to deliver DAH over time	Aware that key people are driving DAH forward (key young person-orientated practitioners); lack of agreement that DAH legitimate part of work; some are willing to work with others to enable DAH; some are motivated to deliver over time
Collective Action: Do people make DAH work in practice?	DAH is operationalisable, especially within network; trust people in network to enact DAH, but less trust beyond; right mix of skills and training to undertake DAH in network, again, less beyond; in one site, clear support for DAH in organisation	Diverse views on workability of DAH and on trust about whether the right people are enacting DAH; lack of skills to undertake DAH, with training offered a one site; in one site, clear support for DAH in organisation
Reflexive Monitoring: Do people evaluate DAH as worthwhile?	Aware of impact of DAH; assess DAH as worthwhile and individually assess DAH as working well; enact DAH flexibly	Unsure of impact of DAH; unsure of whether worthwhile (given competing demands) or working well in practice; may enact some elements of DAH flexibly

Standards for Reporting Qualitative Research (SRQR)*

<http://www.equator-network.org/reporting-guidelines/srqr/>

Page/line no(s).

Title and abstract

<p>Title - Concise description of the nature and topic of the study Identifying the study as qualitative or indicating the approach (e.g., ethnography, grounded theory) or data collection methods (e.g., interview, focus group) is recommended</p>	Page 1
<p>Abstract - Summary of key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results, and conclusions</p>	Page 1

Introduction

<p>Problem formulation - Description and significance of the problem/phenomenon studied; review of relevant theory and empirical work; problem statement</p>	Page 4
<p>Purpose or research question - Purpose of the study and specific objectives or questions</p>	Page 4

Methods

<p>Qualitative approach and research paradigm - Qualitative approach (e.g., ethnography, grounded theory, case study, phenomenology, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g., postpositivist, constructivist/ interpretivist) is also recommended; rationale**</p>	Page 5
<p>Researcher characteristics and reflexivity - Researchers' characteristics that may influence the research, including personal attributes, qualifications/experience, relationship with participants, assumptions, and/or presuppositions; potential or actual interaction between researchers' characteristics and the research questions, approach, methods, results, and/or transferability</p>	Page 5
<p>Context - Setting/site and salient contextual factors; rationale**</p>	Page 5
<p>Sampling strategy - How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g., sampling saturation); rationale**</p>	Page 5
<p>Ethical issues pertaining to human subjects - Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues</p>	Page 5
<p>Data collection methods - Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of sources/methods, and modification of procedures in response to evolving study findings; rationale**</p>	Page 5

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3	Data collection instruments and technologies - Description of instruments (e.g.,	
4	interview guides, questionnaires) and devices (e.g., audio recorders) used for data	
5	collection; if/how the instrument(s) changed over the course of the study	Page 5
6		
7	Units of study - Number and relevant characteristics of participants, documents,	
8	or events included in the study; level of participation (could be reported in results)	Page 6, Table 1
9		
10	Data processing - Methods for processing data prior to and during analysis,	
11	including transcription, data entry, data management and security, verification of	
12	data integrity, data coding, and anonymization/de-identification of excerpts	Page 6
13		
14	Data analysis - Process by which inferences, themes, etc., were identified and	
15	developed, including the researchers involved in data analysis; usually references a	
16	specific paradigm or approach; rationale**	Page 6
17		
18	Techniques to enhance trustworthiness - Techniques to enhance trustworthiness	
19	and credibility of data analysis (e.g., member checking, audit trail, triangulation);	
20	rationale**	Page 6

Results/findings

23	Synthesis and interpretation - Main findings (e.g., interpretations, inferences, and	
24	themes); might include development of a theory or model, or integration with	
25	prior research or theory	Page 6-12
26		
27	Links to empirical data - Evidence (e.g., quotes, field notes, text excerpts,	
28	photographs) to substantiate analytic findings	Page 6-12
29		

Discussion

32	Integration with prior work, implications, transferability, and contribution(s) to	
33	the field - Short summary of main findings; explanation of how findings and	
34	conclusions connect to, support, elaborate on, or challenge conclusions of earlier	
35	scholarship; discussion of scope of application/generalizability; identification of	
36	unique contribution(s) to scholarship in a discipline or field	Page 12-14
37		
38	Limitations - Trustworthiness and limitations of findings	Page 13
39		

Other

42	Conflicts of interest - Potential sources of influence or perceived influence on	
43	study conduct and conclusions; how these were managed	Page 3
44		
45	Funding - Sources of funding and other support; role of funders in data collection,	
46	interpretation, and reporting	Page 3
47		

*The authors created the SRQR by searching the literature to identify guidelines, reporting standards, and critical appraisal criteria for qualitative research; reviewing the reference lists of retrieved sources; and contacting experts to gain feedback. The SRQR aims to improve the transparency of all aspects of qualitative research by providing clear standards for reporting qualitative research.

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**The rationale should briefly discuss the justification for choosing that theory, approach, method, or technique rather than other options available, the assumptions and limitations implicit in those choices, and how those choices influence study conclusions and transferability. As appropriate, the rationale for several items might be discussed together.

Reference:

O'Brien BC, Harris IB, Beckman TJ, Reed DA, Cook DA. **Standards for reporting qualitative research: a synthesis of recommendations.** *Academic Medicine*, Vol. 89, No. 9 / Sept 2014
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Can we normalize developmentally appropriate health care for young people in UK hospital settings? An ethnographic study

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Keywords:	Adolescent Medicine, Adolescent Health Services, Developmentally Appropriate Healthcare, QUALITATIVE RESEARCH, Young Adults

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Can we normalize developmentally appropriate health care for young people in UK hospital settings? An ethnographic study

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ABSTRACT

Objective The World Health Organisation has argued that adolescent-responsive health systems are required. Developmentally appropriate healthcare (DAH) for young people is one approach that could underpin this move. The aim of this study was to explore the potential for DAH to become normalized, to become a routine, taken-for-granted, element of clinical practice.

Design Qualitative ethnographic study. Analyses were based on procedures from first-generation grounded theory and theoretically informed by normalization process theory.

Setting Two tertiary and one secondary care hospital in England.

Participants 192 participants, health professionals (n=121) and managers (n= 71) were recruited between June 2013-January 2015. Approximately 1600 hours of non-participant observations in clinics, wards and meeting rooms were conducted, alongside 65 formal qualitative interviews.

Results We observed diverse values and commitments towards the care of young people and provision of DAH, including a distributed network of young person-orientated practitioners. Informal networks of trust existed, where specific people, teams or wards were understood to have the right skill-mix, or mind-set, or access to resources, to work effectively with young people. As young people move through an organisation, the preference is to direct them to other young person-orientated practitioners, so inequities in skills and experience can be self-sustaining. At two sites, initiatives around adolescent and young adult training remained mostly within these informal networks of trust. At another, through support by wider management, we observed a programme that sought to make the young people's healthcare visible across the organization, and to get people to reappraise values and commitment.

Conclusion To move towards normalization of DAH within an organisation, we cannot solely rely on informal networks and cultures of young person-orientated training, practice and mutual referral and support. Organisation-wide strategies and training are needed, to enable better integration and consistency of health services for all young people.

Strengths and limitations of this study

- This is the first ethnographic study addressing the provision of developmentally appropriate health care for young people.
- Exploring the provision of health care for young people over time, within specific teams and specialities, as well as across an organisation, enabled us to explore the diversity of ways that health care for young people is currently delivered within and across professionals, teams, wards and organisations.
- We only focused on three different organisations and all these organisations had a reputation for undertaking research on the care young people, so may represent examples of 'good practice'.

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54 **Supplementary Files:** Original Protocol; Standards for Reporting Qualitative Research (SRQR)
55 Checklist.
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INTRODUCTION

The health of young people, defined by the World Health Organisation as any person between ages 10 and 24 years,[1] is a neglected yet pressing global issue [2] affecting the largest generation in history.[3] Youth-friendly healthcare [4], promoted as a means to improve health services for young people, has underpinned quality of care and policy frameworks.[5-7] However, as highlighted by the WHO, there is the need to move from the ad hoc provision of youth-friendly healthcare services – often embedded in specific locations or teams - to adolescent-responsive healthcare systems [8]. All the aspects of health and social care that young people engage with, the range of providers, organisations and policies, need to more responsive to and aligned with the care of young people. Other work has also noted that health system-level strategies are needed to further develop and improve healthcare for young people [9,10]. Healthcare providers need to respond to young people's changing developmental needs in a manner that is consistent, universal and provided across healthcare settings. Such adolescent-responsive health systems should be flexible, and should focus on a broad range of aspects of healthcare provision, from the frontline (such as how healthcare professionals communicate with young people) through to the higher levels of healthcare provision (such as how services are planned and commissioned).

Developmentally appropriate healthcare (DAH) for young people [11-13] is one concept that could underpin an adolescent-responsive healthcare system (See Table 1).

Table 1: The five dimensions of Developmentally appropriate healthcare (DAH)

Dimensions of DAH for Young People ⁹⁻¹¹

Biopsychosocial development and holistic care: a focus on biopsychosocial development rather than chronological age, with routine biopsychosocial developmental assessment and approach to the young person adjusted accordingly

Acknowledgement of young people as a distinct group: the recognition that their specific needs - in terms of informational resources, services, spaces, pathways and required competencies of staff - are distinctly different to those of younger children and older adults as a result of their developmental status.

Adjustment of care as the young person develops: the need for flexibility to acknowledge the biopsychosocial developmental changes over time and the potential for regression in relapsing health conditions

Empowerment of the young person by embedding health education and health promotion: that knowledge and skills training for young people is embedded into routine clinical practice to enable them to gradually become more autonomous with respect to the care of their own health as they grow up. Services need to be designed so as to nurture and support such skill development.

Interdisciplinary and Inter-organisational work: a focus on continuity of care, coordination, consistency

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3 and communication across agencies. Connecting health, education, employment, social, voluntary
4 agencies at a clinical and system level.
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10 In contrast to the more service-focussed nature of the youth friendly health service [14], DAH
11 addresses the clinical approach to individual young people and specifically recognises the changing
12 developmental needs of young people and the role of healthcare in addressing and supporting
13 young people. DAH focuses on biopsychosocial development rather than chronological age.
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15 Chronological age is recognised to be a poor indicator of developmental status particularly in the
16 context of a long-term health condition [15]. Young people make this journey to adulthood in their
17 own way; young people's development does not have a fixed period attached to it. Many
18 developmental milestones are met after reaching the legal age of adulthood [16,17].
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22 Services underpinned by DAH have been reported nationally and internationally as a potential key
23 mechanism to improve health outcomes for young people.[3,18] Increasing knowledge about the
24 development of young people [19,20] offers unprecedented opportunities for service improvement.
25 In the context of sub-optimal provision of healthcare for young people,[3,8] DAH offers the potential
26 to transform traditional models of healthcare delivery into adolescent-responsive healthcare
27 systems. However, the concept of DAH has been operationalized in a range of ways in the medical
28 literature [11] and is understood in different ways by clinicians and managers in the NHS [12]. In this
29 study, theoretically informed by Normalization Process Theory (NPT)[21], we investigated the
30 potential for normalization of DAH within three UK hospitals. NPT identifies, characterises, and
31 explains aspects of individual and collective behaviour shown to be important in empirical studies of
32 the introduction, embedding and integration of change [21]. Normalization is achieved when a
33 technique, technology or organisational change becomes a routine and taken-for-granted element
34 of clinical practice.
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48 **METHODS**

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51 This ethnographic study was conducted across three hospitals in two regions of England (a district
52 general hospital, a large paediatric tertiary hospital and a large adult tertiary hospital) all in urban
53 settings outside London. All hospitals had a history of championing research and innovative service
54 provision for young people. At the start of the fieldwork one site – the General Hospital - was
55 developing a policy about DAH. This had emerged from a formal, organisationally-supported, group
56 that focused on the care of young people, that was initially formed to focus on transition. This
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strategy group comprised of managers and senior clinicians. At another site - the Paediatric Hospital - there was no explicit policy on DAH, but one focused on transition. They also had a formal, organisationally-supported, group focused on young people. However, thinking about DAH was being driven by enthusiasts alone. Finally, the third site had no policy on DAH, transition or young people. The sole organisation-wide initiative is an informal interest group focused on young people issues. Health professionals, recruited through six medical and surgical specialties (Diabetes, Emergency Care, General Paediatrics, Outpatients, Rheumatology, and Trauma and Orthopaedics), were chosen to represent the heterogeneous services found in UK National Health Service (NHS) hospitals. Managers were recruited at each site when their roles were relevant to the provision of services for young people in paediatrics and/or adult care. The study received a favourable opinion from the National Research Ethics Committee (12/NE/0423).

Data collection took place over three phases, between June 2013 and January 2015. Recruitment was initially mediated through gatekeepers. Participants were purposively sampled, initially through maximum variation sampling and then refined through snowball and theoretical sampling. [22] Participants were approached to take part in the study using a variety of methods including face-to-face, telephone and email. A total of 192 participants (professionals and managers) were recruited (Table 2).

Table 2 - Recruitment for the study by site, type of staff and method of data collection

		District General Hospital	Paediatric Tertiary Hospital	Adult Tertiary Hospital	Total
Participants observed only	Health professionals	53	22	10	85
	Managers	43	0	12	55
	Total	96	22	22	140
Participants interviewed only	Health professionals	0	14	9	23
	Managers	0	5	2	7
	Total	0	19	11	30
Participants interviewed and observed	Health professionals	8*	4	1	13
	Managers	5*	1	3	9
	Total	13	5	4	22

Total number of participants	109	46	37	192
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*Participants interviewed twice

Approximately 1600 hours of non-participant observations were conducted by two researchers, (AF, VW) alongside 65 formal qualitative interviews. Researchers had specific training and extensive experience in conducting qualitative research and had no relationship with the participants. Observations were conducted within and across a wide variety of hospital spaces – including clinics, wards and meeting rooms - depending on the nature of the session and/or the professionals involved. They were recorded in contemporaneous fieldnotes. Formal interviews (average length, 45 minutes) were conducted face-to-face on a one-to-one basis and were audio-recorded, transcribed, edited to ensure respondents anonymity and then analysed alongside anonymised fieldnotes. Initial topic guides were designed for clinicians and managers irrespective of setting and evolved during the course of data collection, allowing for tailoring and gradual integration of a variety of follow-up issues and topics of relevance to specific roles, settings, specialities or areas. Observation and interviews focused on the organisation of services for young people, including (intra-/inter-) organisational, team and individual aspects of provision, training and support, and patient involvement as well as emerging topics identified through concurrent data analysis.

All analysis was conducted according to the standard procedures of rigorous qualitative analysis by AF, VW and TR.[23] We used procedures from first-generation grounded theory - coding, constant comparison, memoing [24] - and from analytic induction, deviant case analysis.[25] Sampling, data collection and analysis occurred concurrently, so that issues raised in earlier phases of fieldwork were explored subsequently to enable conceptual saturation [26]. We undertook independent coding and cross checking, team data sessions and member validation with some of the participants in the fieldwork. The analysis was assisted by QSR NVivo 10 software and theoretically-informed by Normalization Process Theory[21]. In presenting the analysis, we have drawn on interview quotes, over excerpts from fieldnotes, as they offer the reader rapid access to the key analytic ideas.

Patient and Public Involvement

This study was part of a larger longitudinal programme of research focused on the commissioning and provision of healthcare services for young people [27,28]. The research questions for the programme were initially informed by engagements with a pre-existing young people's advisory group, third-sector voluntary agencies and pupils from a school for young people with physical impairments and students from a living skills course at a college. A young people's advisory group

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2 was established as part of programme and supported all studies within the programme. The group
3 advised on practical (e.g. recruitment) and conceptual issues (e.g. design of study, discussion of key
4 findings and concepts) for this specific study. Young people led on aspects of dissemination,
5 including the production of a video about DAH, for this study.
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11 RESULTS

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14 We identified diverse values and commitments towards the care of young people and provision of
15 DAH across organisations, specialities and staff. We observed a range of informal cultures of good
16 practice implementing core elements of DAH, alongside formal and informal cultures of training
17 around DAH and the provision of care of young people.
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21 Diverse values and commitments

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24 When discussing the provision of care for young people, many focused on the need to create a more
25 age appropriate environment, in terms of physical space, the visual and material culture of waiting
26 room and wards. Others, especially those who worked regularly with young people, discussed
27 features such as appropriate communication, confidentiality and a more holistic focus. As one
28 manager noted:
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33 The young people have told us that, um, we need, they're not bothered about where they
34 are seen so, as in, what the building's look like or what the clinic room looks like. They want
35 to make sure that they see somebody who's interested and who knows what their disease is
36 like, but also has an awareness of all the other stuff that's going on when they're 16 to 18
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39 (Manager, General Hospital)
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42 At this hospital, involvement was considered to be part of patient experience, and young people
43 were involved in such activities as the, attendance at governance meetings and training of staff.
44 Young people's experiences were an important influence on this manager's understanding of
45 'appropriate' service provision.
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50 There were conflicting views on the value and worth of enacting DAH across the organisations. The
51 numbers of young people accessing health services were often portrayed as small, so in
52 organisational terms they were 'just below the radar'. In contrast to older, especially elderly
53 patients, they were also seen as 'very rarely unwell'. This led some to question whether
54 professionals should be adjusting their practices or offering distinct, tailored, services, as there are
55 always competing demands for resources, time and expertise.
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It's small enough [numbers] that if you don't, if you don't buy into it, there's plenty to be getting on with the other 90%. And everybody's jobs are so frantic that you could easily do a very good job with that 90% who are 25, 26 plus. ... So, you could actually ignore these young people completely. (Manager, Adult Hospital)

Questions of legitimacy and buy-in, or rather, enrolment, are central to individual, team and organisational change. In part, this lack of capacity and willingness seems to be compounded by the liminal status of young people within the organisational and professional culture of the UK healthcare system:

Adults don't really want them because they are too young and the paediatricians don't really want them because they are too old (Health Professional, General Hospital).

With the exception of charity-supported oncology wards, adolescent only wards, or spaces within wards, were rare and were often subject to dissolution if there were competing demands. None of the sites had a senior clinical or management lead with responsibility for young people's service development.

However, across all the sites we did observe a complex network of young person-orientated practitioners, people acting as young people 'enthusiasts', or 'champions', within specific clinical or management teams in either a formal or informal capacity. Some specific services and practices were organised around the care of young people. However, relying on the enthusiasm and willingness of specific individuals can become problematic.

Several people have left, who have been very senior members and very adolescent minded and have been replaced by either rotational posts or part-time posts, so that continuity within our team and the wealth of expertise has been impacted on significantly. (Health Professional, Paediatric Hospital).

A focus on champions raises key questions about the sustainability of services for young people over time.

Informal cultures of good practice

Across all three hospitals, we observed local cultures – in teams, clinics, wards and meetings – where professionals attempted to enact a philosophy of care towards young people. They were driven by an awareness of how approaching young people in a different way can mean that young people 'might take the right messages away, might not end up neglecting their health needs, damaging

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2 themselves' (Manager, General Hospital). For these professionals, working with young people
3 required a specific mind-set and skill-set.
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7 At its simplest level this often involved the ability of the professional, or the multi-disciplinary team,
8 to communicate effectively, listening to young people about their health needs and asking them
9 questions, about their broader psychosocial situation. Care is contextualised by gathering
10 information about a young person's life, including educational, vocational, social, friendship and
11 family issues; and exploring risk and resilience factors. Such information is used by teams to
12 generate an appropriate context for effective communication, inform interventions and to organise
13 consultations, including offering appropriate health education and support for self-management.
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19 Providing an appropriate service for young people is often a deeply rooted value for these
20 individuals and groups. The 'You're Welcome Quality Criteria' [6] were generally well known,
21 including core issues such confidentiality and consent, joined-up working, transition and
22 accessibility. Within the context of adult care, failure to attend appointments was a prevalent issue.
23 Ways of dealing with this varied and we were told about what was referred to as, 'a softer approach
24 to the DNAs (did not attend)'
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30 The organisation ruling of one strike and you're out, we don't adhere to, so we will give
31 them multiple attempts to come into clinic ... we don't actually put them as a DNA, because
32 they just booked in [the consultants] calendar but we don't actually book it on the system so
33 they don't officially come as a DNA ... So I'll make informal appointments with the young
34 people and then, when they arrive we book them into clinic, so that way they don't DNA
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39 (Health Professional, Adult Hospital).
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41 Working creatively within the existing norms, rules and resources was characteristic of those who
42 believed that young people needed to be recognized as a group with specific needs and approaches.
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45 We observed across all the organisations 'lots of great pockets of work' as some specialties, teams,
46 people or spaces offered very strong young person-orientated care. However, not all people or
47 services felt it relevant to make 'special arrangements', but chose instead to treat young people like
48 'an ordinary patient'. Alongside this, the uneven distribution of resources within and across
49 specialties created inequities of care.
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54 There are ... areas in the hospital who, because they have more funding or they're funded in
55 a different way, they might have a youth worker because it's part of their team and just for
56 their team. They might have a psychologist who is just part of their team. ... it very much
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2 depends on what speciality you're unfortunate to fall into, depending on what illness you've
3 got as to what service you then get. ... (Health Professional, Paediatric Hospital)
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7 However, resources were not the only source of inequities. In part the inequities in skills and
8 experience across the organisations seemed to be self-sustaining within organisations. Those with
9 an interest, the 'enthusiasts', were embedded in an informal network of care.
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12 we've now got a group of interested people across the [organisation]. So if a young person
13 comes to me and they've got a, a joint problem, but they've also got a bowel problem, I
14 know which bowel consultant and which bowel nurse will be the most appropriate to send
15 them to. ... Um, so we've got a good group of people across the [organisation] that we can
16 actually send these youngsters to who've got more awareness of the issues that they could
17 have (Health Professional, General Hospital)
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23 An informal knowledge economy of young person-orientated practitioners and practices existed
24 within the organisations. These were networks of trust. These referrals helped to create, sustain
25 and reinforce the network over time. This practice also existed across organisations, especially in
26 terms of the transfer of young people to adult services. Young person-orientated practitioners
27 referred to other young person-orientated practitioners – in this way, they worked to actively avoid
28 referring young people to those they felt maybe less young person-orientated. These people then
29 gained less practical experience with managing these patients, and so had less chance to reappraise
30 their values and commitment to working with young people in new ways, as well as to develop the
31 right skill-mix.
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39 An informal network also existed in terms of spaces. At each site, at least one specific ward was
40 known to offer more young person-orientated care. They were seen as repositories of knowledge
41 and skills, able to advise on or manage potentially challenging behaviour.
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45 We were getting so much enquiries regarding adolescents from the other wards, even just
46 for the basics. ... So, they would ring us and say, "We can't get them out of bed in the
47 morning". You know, "they just want to stay in bed all the time and they don't want to
48 interact with anything". So we would say, "Well then you have to be stern, you know, you
49 have to tell them, 'This is the plan,' you have to do a contract with them and agree with
50 them that if they get over this time, then they can do this at this time" (Health Professional,
51 Paediatric Hospital).
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3 It is not only that 'just different wards have a different tolerance', but rather that different wards
4 and teams, developed, over time, different understanding and a different sense of what was
5 legitimate work, as well as developmentally appropriate skills, competencies and routines.
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9 In some situations, we've had patients on our general wards where the parent has wanted
10 to stay. And we, my nurses, would find that very strange. But actually, in oncology, that
11 would not be strange at all. Because ... [they] would be used to that, even a patient could be
12 22, 23 and still may want their mum. But they're not exposed to that in the main wards.
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14 (Health Professional, Adult Hospital)
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18 Exposure to working with young people was central to adjusting expectations, enabling them to
19 longer see young people as having 'strange' requests or being particularly 'difficult' to work with.
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21 Exposure offered a chance to develop new skills.
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23 **(In)formal cultures of training**

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26 Within each of the organisations there were formal and informal groups at which the young person-
27 orientated enthusiasts met and supported each other collectively. Essentially, these groups were a
28 collective effort to promote initiatives to raise awareness across the organisations, create change,
29 offer support and, importantly, learn from each other outwith their team, area or specialty.
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34 I have nothing in writing in my job plan that says I specialise in young people. ... Nobody said,
35 "If you want to be a young adult person, you need to go on this [training course]". It's just
36 something that I became aware of through organisations or talking to people. So, it's all
37 quite ad-hoc rather than really, really planned. And it's just really by hearsay and talking to
38 people and networking throughout [this organisation] over many years. (Health Professional,
39 Paediatric Hospital)
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45 Without any formalised professional routes available, the local, regional and national special
46 interests groups became a central resource for supporting adolescent and young adult health
47 training across the organisations.
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51 At two hospitals, the only initiatives involving training around young people originated from their
52 respective special interest groups, in the form of annual study days. At one of these hospitals, there
53 was a policy initiative explicitly around transition, yet no specific training had been organised. At the
54 other, development of a formal policy was said to be 'not a priority for the organisation'.
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59 Priorities are the front door, A&E [Accident and Emergency], Clinical Decisions Unit, waiting
60 times and, it's those things that they are being judged on.

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2 Interviewer: Why do you think this is not a priority at all?
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5 Just because they've got bigger fish to fry. ... But it's not a priority for the [organization]
6 because of all the other things by which they are measured. And young people's care isn't on
7 that list. (Manager, Adult Hospital)
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11 In the current context of the factors that drove organisational change at this site, creating further
12 engagement and buy-in from senior management were not seen as practical solution. Issues about
13 the care of young people remained focused in the informal, organisation-wide group, of young
14 people's enthusiasts. As we discovered, not everyone interested in the care of young people in that
15 organisation was aware of the existence of that group. Even those within the group were often
16 unaware of the range of young person-orientated initiatives that were occurring within their
17 organisation.
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23 At the remaining hospital specific training around the topic of DAH was observed being planned and
24 delivered. A DAH strategy emerged as the result of the work of key people who sat on a transition
25 strategy group. The group comprised of managers and health professionals, who met bi-monthly.
26 There was strong cross-over between managerial and clinical levels and they worked to actively
27 foster communication and create connections across services. The ideas emerged from the local
28 special interest group, but the dissemination was targeted well beyond that group. Part of this
29 involved looking where change was currently occurring within the organisation, alongside the
30 broader national agendas on young people's health, in order to harness that momentum and get
31 people involved.
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40 The focus of the strategy and training was on organisational level factors (e.g. staff appraisal
41 including training goals around young people; provision of age-banded clinics), clinic and
42 consultation level factors (e.g. signpost sexual health, drug and alcohol services; copying clinic letters
43 to young people), and training and awareness factors (e.g. adolescent development; confidentiality).
44 This programme of training had senior management support, albeit initially only from child health,
45 alongside access to resources. Using money to 'back fill' was seen as a key component in the success
46 of the roll-out of training, as without this departments would not only be unwilling but also unable
47 to release staff for training.
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54 Last year we did, um, we did ten days, so ten individual day sessions for training in
55 adolescent, basic adolescent health. Basically to increase awareness across the
56 [organisation] so as to make sure it wasn't just the, the chronic illness patients that were
57 being looked at ... but it was the patients coming through A&E, coming through X-ray ... just
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to get them aware of what a young person's needs are and why they're different to being an adult (Health Professional, General Hospital).

Central norms and practices of good, everyday, care for young people were distributed well beyond the local existing networks. The initiative emerged from, and depended on, their enthusiasm and expertise. The network of trust of young person-orientated practitioners was then supported by key actors within wider management. This led to an on-going training programme that sought to make the young people's healthcare visible across the organization, to begin to get to people to reappraise values and commitment.

DISCUSSION

Across each organisation a complex, distributed, network of adolescent-oriented practitioners understood the potential value and worth of practices and services for young people, such as DAH. Within and across organisations there is an informal knowledge economy of young people-oriented practitioners, teams and spaces. People have a preference for referring to other young person-orientated practitioners or spaces, to others within their networks of trust. Such referrals help to create, sustain and reinforce the network over time. As such we see evidence of strong communities of practice [29], focused on supporting and enacting adolescent medicine. Table 3 illustrates our results in relation to the four theoretical constructs of normalization process theory (NPT),[21].

Table 3: The four constructs of Normalization Process Theory (NPT) mapped against practitioner groups

NPT Construct	Networks of young person-oriented practitioners and managers	Other practitioners and managers who work with young people
Coherence: Do people make sense of DAH?	See how DAH extends and is related to other approaches to care of young people; relatively shared understanding of purpose of DAH; understanding of impact of DAH on their work; and see potential value and worth of DAH	Diverse views on relationship to other approaches; lack of shared understanding of purpose of DAH; diverse understanding of potential impact of DAH on their work; uncertainty around of potential value and worth (especially, given competing demands)
Cognitive Participation: Do people get involved with providing DAH and stay committed?	They are the key people driving DAH forward; they see DAH as legitimate, generally core, part of role; are very willing to work with others to enable DAH; and motivated to deliver DAH	Aware that key people are driving DAH forward (key young person-orientated practitioners); lack of agreement that DAH legitimate part of work; some are willing to work with others to enable

	over time	DAH; some are motivated to deliver over time
Collective Action: Do people make DAH work in practice?	DAH is operationalisable, especially within network; trust people in network to enact DAH, but less trust beyond; right mix of skills and training to undertake DAH in network, again, less beyond; in one site, clear support for DAH in organisation	Diverse views on workability of DAH and on trust about whether the right people are enacting DAH; lack of skills to undertake DAH, with training offered a one site; in one site, clear support for DAH in organisation
Reflexive Monitoring: Do people evaluate DAH as worthwhile?	Aware of impact of DAH; assess DAH as worthwhile and individually assess DAH as working well; enact DAH flexibly	Unsure of impact of DAH; unsure of whether worthwhile (given competing demands) or working well in practice; may enact some elements of DAH flexibly

The potential for normalization of DAH is high within the group of young person-oriented practitioners and managers, as they make sense of, buy-into, enact, and evaluate it as worthwhile. Beyond the networks of young person-oriented practitioners and managers, we observed a low potential for normalization. There are differences in opinion about the meaning and worth of DAH, its organisational and policy relevance, its potential workability, and its resource and spatial allocation. At one hospital, providing an organisation-wide strategy and training offered a clear opportunity to increase the potential for normalization of DAH. Although not mandated, this programme of training, with support to 'back fill' those attending it, offered the greatest potential for an increase in people seeing (aspects of) DAH as legitimate, to increase buy-in and enrolment. This training has the potential to further extend the networks of young person-oriented practitioners and managers. It relied on buy-in and formal support from senior managers in both child and adult services to initiate and sustain it. The other two sites lacked any formal policy initiatives and any formal support and so had, at the time of fieldwork, a low potential to transform values and commitment across their respective organisations. At the start of the fieldwork, there was no national guidance on DAH. However, since the fieldwork, national guidance on transition [18] states that such care should be developmentally appropriate. This has the potential to enable change. The formal and informal groups with an interest in young peoples care at those sites would clearly need buy-in and formal support from senior managers.

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10 This is the first ethnographic study addressing the area of developmentally appropriate health care
11 for young people. This study gathered considerable data from many sources. The focus on exploring
12 the provision of health care for young people over time, within specific teams and specialities, as
13 well as across an organisation, enabled us to demonstrate the diversity within and across
14 professional, team, ward and organisational boundaries. However, we only focused on three
15 different organisations. Notably, all these organisations had a reputation for undertaking research
16 on the care young people, so may represent examples of 'good practice'. Given the timing of our
17 fieldwork, we did not get the opportunity to observe the impact of the roll-out of training around
18 DAH that occurred at the one of the NHS trusts. A potential limitation of the study is that no young
19 people were interviewed. However there is a large literature of young people's experience in
20 hospital settings but much less literature focussing on the perspective of health professionals and
21 particularly of hospital managers.
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32 Policy and research has emphasised the centrality of service delivery and workforce capacity issues
33 to achieve successful integration and consistency of health services for all young people across
34 organisations [8, 9]. The results presented here add to this evidence base as we observed how the
35 community of practice, the networks of young person-orientated practitioners and managers also
36 support and provide, through formal and informal means, training and development around young
37 people's health. Previous research has shown that continuing medical education in adolescent
38 health, can increase developmentally appropriate practices (such as confidential services) and has
39 the potential to address systemic barriers to healthcare for young people.[30] Thus, the role of such
40 networks may be vital to achieving any sustainable change in the provision of healthcare for young
41 people. Across all the sites, young people's formal and informal champions were key to getting
42 people involved in the healthcare of young people. Research has outlined the importance of staff
43 attitudes as a key determinant of young people's satisfaction with care.[4, 31] Prior research has
44 also shown the problem of staff turnover, if services rely on key individuals [32,33] . As such, there
45 needs to be consistency of approach to developing local cultures of good practice that can withstand
46 changes in personnel. In primary care, the Adolescent Champion model, which trains a
47 multidisciplinary team of practice staff to deliver training to other staff and implement local quality
48 improvement, has shown potential for sustainable change [34].
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4 Our findings suggest that there is a need for strong and clear guidelines, strategies and policies on
5 the practical implementation of DAH at three levels: those of the individual young person and their
6 family, the multidisciplinary team level and the organisation and/or system level. Our research
7 informed the development of a toolkit for implementation of DAH at these levels which includes
8 description of the models of good practice in terms of multidisciplinary working and training at the 3
9 hospitals studied [35,36]. Since the fieldwork ended, additional guidance has been published
10 including for the care of young people in acute care settings [37] which includes a focus on DAH,
11 alongside national guidance on the need to implement DAH in relation to transitional care.[18] A
12 focus on specific settings (like acute care) or contexts (like transition) has limitations as it can
13 introduce or sustain inequities. Buy-in and formal support from senior managers in both child and
14 adult services seems essential. Providing an institution-wide strategy and training seems key,
15 particularly in view of the current unmet training needs reported in both paediatric [38] and adult
16 physicians [39]. Currently adolescent and young adult medicine is not a recognised discipline in its
17 own right in the UK unlike Australia and North America [40] although even when it is an established
18 discipline, challenges remain, for example in the USA [41]. The 'informal' adolescent and young adult
19 medicine community in the UK may also need to become more formally recognised. Young people
20 should no longer be seen as 'vary rarely ill' or allowed to remain 'just below the radar', or seen as
21 'too old' for child services or 'too young' for adult. Core principles underlying the practice of
22 adolescent medicine, such as DAH, should not remain contested. We need to enable people to
23 reappraise values and commitment, to understand them as a normal part of everyday service
24 provision.
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Standards for Reporting Qualitative Research (SRQR)*

<http://www.equator-network.org/reporting-guidelines/srqr/>

Page/line no(s).

Title and abstract

<p>Title - Concise description of the nature and topic of the study Identifying the study as qualitative or indicating the approach (e.g., ethnography, grounded theory) or data collection methods (e.g., interview, focus group) is recommended</p>	Page 1
<p>Abstract - Summary of key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results, and conclusions</p>	Page 1

Introduction

<p>Problem formulation - Description and significance of the problem/phenomenon studied; review of relevant theory and empirical work; problem statement</p>	Page 4
<p>Purpose or research question - Purpose of the study and specific objectives or questions</p>	Page 4

Methods

<p>Qualitative approach and research paradigm - Qualitative approach (e.g., ethnography, grounded theory, case study, phenomenology, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g., postpositivist, constructivist/ interpretivist) is also recommended; rationale**</p>	Page 5
<p>Researcher characteristics and reflexivity - Researchers' characteristics that may influence the research, including personal attributes, qualifications/experience, relationship with participants, assumptions, and/or presuppositions; potential or actual interaction between researchers' characteristics and the research questions, approach, methods, results, and/or transferability</p>	Page 5
<p>Context - Setting/site and salient contextual factors; rationale**</p>	Page 5
<p>Sampling strategy - How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g., sampling saturation); rationale**</p>	Page 5
<p>Ethical issues pertaining to human subjects - Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues</p>	Page 5
<p>Data collection methods - Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of sources/methods, and modification of procedures in response to evolving study findings; rationale**</p>	Page 5

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3	Data collection instruments and technologies - Description of instruments (e.g.,	
4	interview guides, questionnaires) and devices (e.g., audio recorders) used for data	
5	collection; if/how the instrument(s) changed over the course of the study	Page 5
6		
7	Units of study - Number and relevant characteristics of participants, documents,	
8	or events included in the study; level of participation (could be reported in results)	Page 6, Table 1
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10	Data processing - Methods for processing data prior to and during analysis,	
11	including transcription, data entry, data management and security, verification of	
12	data integrity, data coding, and anonymization/de-identification of excerpts	Page 6
13		
14	Data analysis - Process by which inferences, themes, etc., were identified and	
15	developed, including the researchers involved in data analysis; usually references a	
16	specific paradigm or approach; rationale**	Page 6
17		
18	Techniques to enhance trustworthiness - Techniques to enhance trustworthiness	
19	and credibility of data analysis (e.g., member checking, audit trail, triangulation);	
20	rationale**	Page 6

Results/findings

23	Synthesis and interpretation - Main findings (e.g., interpretations, inferences, and	
24	themes); might include development of a theory or model, or integration with	
25	prior research or theory	Page 6-12
26		
27	Links to empirical data - Evidence (e.g., quotes, field notes, text excerpts,	
28	photographs) to substantiate analytic findings	Page 6-12
29		

Discussion

32	Integration with prior work, implications, transferability, and contribution(s) to	
33	the field - Short summary of main findings; explanation of how findings and	
34	conclusions connect to, support, elaborate on, or challenge conclusions of earlier	
35	scholarship; discussion of scope of application/generalizability; identification of	
36	unique contribution(s) to scholarship in a discipline or field	Page 12-14
37		
38	Limitations - Trustworthiness and limitations of findings	Page 13
39		

Other

42	Conflicts of interest - Potential sources of influence or perceived influence on	
43	study conduct and conclusions; how these were managed	Page 3
44		
45	Funding - Sources of funding and other support; role of funders in data collection,	
46	interpretation, and reporting	Page 3
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*The authors created the SRQR by searching the literature to identify guidelines, reporting standards, and critical appraisal criteria for qualitative research; reviewing the reference lists of retrieved sources; and contacting experts to gain feedback. The SRQR aims to improve the transparency of all aspects of qualitative research by providing clear standards for reporting qualitative research.

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**The rationale should briefly discuss the justification for choosing that theory, approach, method, or technique rather than other options available, the assumptions and limitations implicit in those choices, and how those choices influence study conclusions and transferability. As appropriate, the rationale for several items might be discussed together.

Reference:

O'Brien BC, Harris IB, Beckman TJ, Reed DA, Cook DA. **Standards for reporting qualitative research: a synthesis of recommendations.** *Academic Medicine*, Vol. 89, No. 9 / Sept 2014
DOI: 10.1097/ACM.0000000000000388

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Can we normalize developmentally appropriate health care for young people in UK hospital settings? An ethnographic study

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Can we normalize developmentally appropriate health care for young people in UK hospital settings? An ethnographic study

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ABSTRACT

Objective The World Health Organisation has argued that adolescent-responsive health systems are required. Developmentally appropriate healthcare (DAH) for young people is one approach that could underpin this move. The aim of this study was to explore the potential for DAH to become normalized, to become a routine, taken-for-granted, element of clinical practice.

Design Qualitative ethnographic study. Analyses were based on procedures from first-generation grounded theory and theoretically informed by normalization process theory.

Setting Two tertiary and one secondary care hospital in England.

Participants 192 participants, health professionals (n=121) and managers (n= 71) were recruited between June 2013-January 2015. Approximately 1600 hours of non-participant observations in clinics, wards and meeting rooms were conducted, alongside 65 formal qualitative interviews.

Results We observed diverse values and commitments towards the care of young people and provision of DAH, including a distributed network of young person-orientated practitioners. Informal networks of trust existed, where specific people, teams or wards were understood to have the right skill-mix, or mind-set, or access to resources, to work effectively with young people. As young people move through an organisation, the preference is to direct them to other young person-orientated practitioners, so inequities in skills and experience can be self-sustaining. At two sites, initiatives around adolescent and young adult training remained mostly within these informal networks of trust. At another, through support by wider management, we observed a programme that sought to make the young people's healthcare visible across the organization, and to get people to reappraise values and commitment.

Conclusion To move towards normalization of DAH within an organisation, we cannot solely rely on informal networks and cultures of young person-orientated training, practice and mutual referral and support. Organisation-wide strategies and training are needed, to enable better integration and consistency of health services for all young people.

Strengths and limitations of this study

- This is the first ethnographic study addressing the provision of developmentally appropriate health care for young people.
- Exploring the provision of health care for young people over time, within specific teams and specialities, as well as across an organisation, enabled us to explore the diversity of ways that health care for young people is currently delivered within and across professionals, teams, wards and organisations.
- We only focused on three different organisations and all these organisations had a reputation for undertaking research on the care young people, so may represent examples of 'good practice'.

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49 **Data availability statement:** No additional data is available. Data are difficult to anonymise and we
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54 **Supplementary Files:** Original Protocol; Standards for Reporting Qualitative Research (SRQR)
55 Checklist.
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INTRODUCTION

The health of young people, defined by the World Health Organisation as any person between ages 10 and 24 years,[1] is a neglected yet pressing global issue [2] affecting the largest generation in history.[3] Youth-friendly healthcare [4], promoted as a means to improve health services for young people, has underpinned quality of care and policy frameworks.[5-7] However, as highlighted by the WHO, there is the need to move from the ad hoc provision of youth-friendly healthcare services – often embedded in specific locations or teams - to adolescent-responsive healthcare systems [8]. All the aspects of health and social care that young people engage with, the range of providers, organisations and policies, need to more responsive to and aligned with the care of young people. Other work has also noted that health system-level strategies are needed to further develop and improve healthcare for young people [9,10]. Healthcare providers need to respond to young people's changing developmental needs in a manner that is consistent, universal and provided across healthcare settings. Such adolescent-responsive health systems should be flexible, and should focus on a broad range of aspects of healthcare provision, from the frontline (such as how healthcare professionals communicate with young people) through to the higher levels of healthcare provision (such as how services are planned and commissioned).

Developmentally appropriate healthcare (DAH) for young people [11-13] is one concept that could underpin an adolescent-responsive healthcare system (See Table 1).

Table 1: The five dimensions of Developmentally appropriate healthcare (DAH)

Dimensions of DAH for Young People ⁹⁻¹¹

Biopsychosocial development and holistic care: a focus on biopsychosocial development rather than chronological age, with routine biopsychosocial developmental assessment and approach to the young person adjusted accordingly

Acknowledgement of young people as a distinct group: the recognition that their specific needs - in terms of informational resources, services, spaces, pathways and required competencies of staff - are distinctly different to those of younger children and older adults as a result of their developmental status.

Adjustment of care as the young person develops: the need for flexibility to acknowledge the biopsychosocial developmental changes over time and the potential for regression in relapsing health conditions

Empowerment of the young person by embedding health education and health promotion: that knowledge and skills training for young people is embedded into routine clinical practice to enable them to gradually become more autonomous with respect to the care of their own health as they grow up. Services need to be designed so as to nurture and support such skill development.

Interdisciplinary and Inter-organisational work: a focus on continuity of care, coordination, consistency

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3 and communication across agencies. Connecting health, education, employment, social, voluntary
4 agencies at a clinical and system level.
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10 In contrast to the more service-focussed nature of the youth friendly health service [14], DAH
11 addresses the clinical approach to individual young people and specifically recognises the changing
12 developmental needs of young people and the role of healthcare in addressing and supporting
13 young people. DAH focuses on biopsychosocial development rather than chronological age.
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15 Chronological age is recognised to be a poor indicator of developmental status particularly in the
16 context of a long-term health condition [15]. Young people make this journey to adulthood in their
17 own way; young people's development does not have a fixed period attached to it. Many
18 developmental milestones are met after reaching the legal age of adulthood [16,17].
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22 Services underpinned by DAH have been reported nationally and internationally as a potential key
23 mechanism to improve health outcomes for young people.[3,18] Increasing knowledge about the
24 development of young people [19,20] offers unprecedented opportunities for service improvement.
25 In the context of sub-optimal provision of healthcare for young people,[3,8] DAH offers the potential
26 to transform traditional models of healthcare delivery into adolescent-responsive healthcare
27 systems. However, the concept of DAH has been operationalized in a range of ways in the medical
28 literature [11] and is understood in different ways by clinicians and managers in the NHS [12]. In this
29 study, theoretically informed by Normalization Process Theory (NPT)[21], we investigated the
30 potential for normalization of DAH within three UK hospitals. NPT identifies, characterises, and
31 explains aspects of individual and collective behaviour shown to be important in empirical studies of
32 the introduction, embedding and integration of change [21]. Normalization is achieved when a
33 technique, technology or organisational change becomes a routine and taken-for-granted element
34 of clinical practice.
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48 **METHODS**

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51 This ethnographic study was conducted across three hospitals in two regions of England (a district
52 general hospital, a large paediatric tertiary hospital and a large adult tertiary hospital) all in urban
53 settings outside London. All hospitals had a history of championing research and innovative service
54 provision for young people. At the start of the fieldwork one site – the General Hospital - was
55 developing a policy about DAH. This had emerged from a formal, organisationally-supported, group
56 that focused on the care of young people, that was initially formed to focus on transition. This
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strategy group comprised of managers and senior clinicians. At another site - the Paediatric Hospital - there was no explicit policy on DAH, but one focused on transition. They also had a formal, organisationally-supported, group focused on young people. However, thinking about DAH was being driven by enthusiasts alone. Finally, the third site had no policy on DAH, transition or young people. The sole organisation-wide initiative is an informal interest group focused on young people issues. Health professionals, recruited through six medical and surgical specialties (Diabetes, Emergency Care, General Paediatrics, Outpatients, Rheumatology, and Trauma and Orthopaedics), were chosen to represent the heterogeneous services found in UK National Health Service (NHS) hospitals. Managers were recruited at each site when their roles were relevant to the provision of services for young people in paediatrics and/or adult care. The study received a favourable opinion from the National Research Ethics Committee (12/NE/0423).

Data collection took place over three phases, between June 2013 and January 2015. Recruitment was initially mediated through gatekeepers. Participants were purposively sampled, initially through maximum variation sampling and then refined through snowball sampling and theoretical. [22] Participants were approached to take part in the study using a variety of methods including face-to-face, telephone and email. A total of 192 participants (professionals and managers) were recruited (Table 2).

Table 2 - Recruitment for the study by site, type of staff and method of data collection

		District General Hospital	Paediatric Tertiary Hospital	Adult Tertiary Hospital	Total
Participants observed only	Health professionals	53	22	10	85
	Managers	43	0	12	55
	Total	96	22	22	140
Participants interviewed only	Health professionals	0	14	9	23
	Managers	0	5	2	7
	Total	0	19	11	30
Participants interviewed and observed	Health professionals	8*	4	1	13
	Managers	5*	1	3	9
	Total	13	5	4	22

Total number of participants	109	46	37	192
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*Participants interviewed twice

Approximately 1600 hours of non-participant observations were conducted by two researchers, (AF, VW) alongside 65 formal qualitative interviews. Researchers had specific training and extensive experience in conducting qualitative research and had no relationship with the participants. Observations were conducted within and across a wide variety of hospital spaces – including clinics, wards and meeting rooms - depending on the nature of the session and/or the professionals involved. They were recorded in contemporaneous fieldnotes. Participants were selected for formal interviews to follow-up specific issues emerging from observation sessions and/or prior interviews. Formal interviews (average length, 45 minutes) were conducted face-to-face on a one-to-one basis and were audio-recorded, transcribed, edited to ensure respondents anonymity and then analysed alongside anonymised fieldnotes. Initial topic guides were designed for clinicians and managers irrespective of setting and evolved during the course of data collection, allowing for tailoring and gradual integration of a variety of follow-up issues and topics of relevance to specific roles, settings, specialities or areas. Observation and interviews focused on the organisation of services for young people, including (intra-/inter-) organisational, team and individual aspects of provision, training and support, and patient involvement as well as emerging topics identified through concurrent data analysis.

All analysis was conducted according to the standard procedures of rigorous qualitative analysis by AF, VW and TR.[23] We used procedures from first-generation grounded theory - coding, constant comparison, memoing [24] - and from analytic induction, deviant case analysis.[25] Sampling, data collection and analysis occurred concurrently, so that issues raised in earlier phases of fieldwork were explored subsequently to enable conceptual saturation [26]. We undertook independent coding and cross checking, team data sessions and member validation with some of the participants in the fieldwork. The analysis was assisted by QSR NVivo 10 software and theoretically-informed by Normalization Process Theory[21]. In presenting the analysis, we have drawn on interview quotes, over excerpts from fieldnotes, as they offer the reader rapid access to the key analytic ideas.

Patient and Public Involvement

This study was part of a larger longitudinal programme of research focused on the commissioning and provision of healthcare services for young people [27,28]. The research questions for the programme were initially informed by engagements with a pre-existing young people's advisory

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3 group, third-sector voluntary agencies and pupils from a school for young people with physical
4 impairments and students from a living skills course at a college. A young people's advisory group
5 was established as part of programme and supported all studies within the programme. The group
6 advised on practical (e.g. recruitment) and conceptual issues (e.g. design of study, discussion of key
7 findings and concepts) for this specific study. Young people led on aspects of dissemination,
8 including the production of a video about DAH, for this study.
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14 RESULTS

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17 We identified diverse values and commitments towards the care of young people and provision of
18 DAH across organisations, specialities and staff. We observed a range of informal cultures of good
19 practice implementing core elements of DAH, alongside formal and informal cultures of training
20 around DAH and the provision of care of young people.
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25 Diverse values and commitments

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27 When discussing the provision of care for young people, many focused on the need to create a more
28 age appropriate environment, in terms of physical space, the visual and material culture of waiting
29 room and wards. Others, especially those who worked regularly with young people, discussed
30 features such as appropriate communication, confidentiality and a more holistic focus. As one
31 manager noted:
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37 The young people have told us that, um, we need, they're not bothered about where they
38 are seen so, as in, what the building's look like or what the clinic room looks like. They want
39 to make sure that they see somebody who's interested and who knows what their disease is
40 like, but also has an awareness of all the other stuff that's going on when they're 16 to 18
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42
43 (Manager, General Hospital)
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45
46 At this hospital, involvement was considered to be part of patient experience, and young people
47 were involved in such activities as the, attendance at governance meetings and training of staff.
48 Young people's experiences were an important influence on this manager's understanding of
49 'appropriate' service provision.
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54 There were conflicting views on the value and worth of enacting DAH across the organisations. The
55 numbers of young people accessing health services were often portrayed as small, so in
56 organisational terms they were 'just below the radar'. In contrast to older, especially elderly
57 patients, they were also seen as 'very rarely unwell'. This led some to question whether
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3 professionals should be adjusting their practices or offering distinct, tailored, services, as there are
4 always competing demands for resources, time and expertise.
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7 It's small enough [numbers] that if you don't, if you don't buy into it, there's plenty to be
8 getting on with the other 90%. And everybody's jobs are so frantic that you could easily do a
9 very good job with that 90% who are 25, 26 plus. ... So, you could actually ignore these
10 young people completely. (Manager, Adult Hospital)
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14 Questions of legitimacy and buy-in, or rather, enrolment, are central to individual, team and
15 organisational change. In part, this lack of capacity and willingness seems to be compounded by the
16 liminal status of young people within the organisational and professional culture of the UK
17 healthcare system:
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22 Adults don't really want them because they are too young and the paediatricians don't really
23 want them because they are too old (Health Professional, General Hospital).
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26 With the exception of charity-supported oncology wards, adolescent only wards, or spaces within
27 wards, were rare and were often subject to dissolution if there were competing demands. None of
28 the sites had a senior clinical or management lead with responsibility for young people's service
29 development.
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33 However, across all the sites we did observe a complex network of young person-orientated
34 practitioners, people acting as young people 'enthusiasts', or 'champions', within specific clinical or
35 management teams in either a formal or informal capacity. Some specific services and practices
36 were organised around the care of young people. However, relying on the enthusiasm and
37 willingness of specific individuals can become problematic.
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43 Several people have left, who have been very senior members and very adolescent minded
44 and have been replaced by either rotational posts or part-time posts, so that continuity
45 within our team and the wealth of expertise has been impacted on significantly. (Health
46 Professional, Paediatric Hospital).
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50 A focus on champions raises key questions about the sustainability of services for young people over
51 time.
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54 **Informal cultures of good practice**

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57 Across all three hospitals, we observed local cultures – in teams, clinics, wards and meetings – where
58 professionals attempted to enact a philosophy of care towards young people. They were driven by
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3 an awareness of how approaching young people in a different way can mean that young people
4 'might take the right messages away, might not end up neglecting their health needs, damaging
5 themselves' (Manager, General Hospital). For these professionals, working with young people
6 required a specific mind-set and skill-set.
7
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10 At its simplest level this often involved the ability of the professional, or the multi-disciplinary team,
11 to communicate effectively, listening to young people about their health needs and asking them
12 questions, about their broader psychosocial situation. Care is contextualised by gathering
13 information about a young person's life, including educational, vocational, social, friendship and
14 family issues; and exploring risk and resilience factors. Such information is used by teams to
15 generate an appropriate context for effective communication, inform interventions and to organise
16 consultations, including offering appropriate health education and support for self-management.
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19
20 Providing an appropriate service for young people is often a deeply rooted value for these
21 individuals and groups. The 'You're Welcome Quality Criteria' [6] were generally well known,
22 including core issues such confidentiality and consent, joined-up working, transition and
23 accessibility. Within the context of adult care, failure to attend appointments was a prevalent issue.
24 Ways of dealing with this varied and we were told about what was referred to as, 'a softer approach
25 to the DNAs (did not attend)'
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34 The organisation ruling of one strike and you're out, we don't adhere to, so we will give
35 them multiple attempts to come into clinic ... we don't actually put them as a DNA, because
36 they just booked in [the consultants] calendar but we don't actually book it on the system so
37 they don't officially come as a DNA ... So I'll make informal appointments with the young
38 people and then, when they arrive we book them into clinic, so that way they don't DNA
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42 (Health Professional, Adult Hospital).
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45 Working creatively within the existing norms, rules and resources was characteristic of those who
46 believed that young people needed to be recognized as a group with specific needs and approaches.
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49 We observed across all the organisations 'lots of great pockets of work' as some specialties, teams,
50 people or spaces offered very strong young person-orientated care. However, not all people or
51 services felt it relevant to make 'special arrangements', but chose instead to treat young people like
52 'an ordinary patient'. Alongside this, the uneven distribution of resources within and across
53 specialties created inequities of care.
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58 There are ... areas in the hospital who, because they have more funding or they're funded in
59 a different way, they might have a youth worker because it's part of their team and just for
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3 their team. They might have a psychologist who is just part of their team. ... it very much
4 depends on what speciality you're unfortunate to fall into, depending on what illness you've
5 got as to what service you then get. ... (Health Professional, Paediatric Hospital)
6
7

8 However, resources were not the only source of inequities. In part the inequities in skills and
9 experience across the organisations seemed to be self-sustaining within organisations. Those with
10 an interest, the 'enthusiasts', were embedded in an informal network of care.
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13
14 we've now got a group of interested people across the [organisation]. So if a young person
15 comes to me and they've got a, a joint problem, but they've also got a bowel problem, I
16 know which bowel consultant and which bowel nurse will be the most appropriate to send
17 them to. ... Um, so we've got a good group of people across the [organisation] that we can
18 actually send these youngsters to who've got more awareness of the issues that they could
19 have (Health Professional, General Hospital)
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25 An informal knowledge economy of young person-orientated practitioners and practices existed
26 within the organisations. These were networks of trust. These referrals helped to create, sustain
27 and reinforce the network over time. This practice also existed across organisations, especially in
28 terms of the transfer of young people to adult services. Young person-orientated practitioners
29 referred to other young person-orientated practitioners – in this way, they worked to actively avoid
30 referring young people to those they felt maybe less young person-orientated. These people then
31 gained less practical experience with managing these patients, and so had less chance to reappraise
32 their values and commitment to working with young people in new ways, as well as to develop the
33 right skill-mix.
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40 An informal network also existed in terms of spaces. At each site, at least one specific ward was
41 known to offer more young person-orientated care. They were seen as repositories of knowledge
42 and skills, able to advise on or manage potentially challenging behaviour.
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47 We were getting so much enquiries regarding adolescents from the other wards, even just
48 for the basics. ... So, they would ring us and say, "We can't get them out of bed in the
49 morning". You know, "they just want to stay in bed all the time and they don't want to
50 interact with anything". So we would say, "Well then you have to be stern, you know, you
51 have to tell them, 'This is the plan,' you have to do a contract with them and agree with
52 them that if they get over this time, then they can do this at this time" (Health Professional,
53 Paediatric Hospital).
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3 It is not only that 'just different wards have a different tolerance', but rather that different wards
4 and teams, developed, over time, different understanding and a different sense of what was
5 legitimate work, as well as developmentally appropriate skills, competencies and routines.
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8 In some situations, we've had patients on our general wards where the parent has wanted
9 to stay. And we, my nurses, would find that very strange. But actually, in oncology, that
10 would not be strange at all. Because ... [they] would be used to that, even a patient could be
11 22, 23 and still may want their mum. But they're not exposed to that in the main wards.
12
13 (Health Professional, Adult Hospital)
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17 Exposure to working with young people was central to adjusting expectations, enabling them to
18 longer see young people as having 'strange' requests or being particularly 'difficult' to work with.
19 Exposure offered a chance to develop new skills.
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23 **(In)formal cultures of training**

24 Within each of the organisations there were formal and informal groups at which the young person-
25 orientated enthusiasts met and supported each other collectively. Essentially, these groups were a
26 collective effort to promote initiatives to raise awareness across the organisations, create change,
27 offer support and, importantly, learn from each other outwith their team, area or specialty.
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33 I have nothing in writing in my job plan that says I specialise in young people. ... Nobody said,
34 "If you want to be a young adult person, you need to go on this [training course]". It's just
35 something that I became aware of through organisations or talking to people. So, it's all
36 quite ad-hoc rather than really, really planned. And it's just really by hearsay and talking to
37 people and networking throughout [this organisation] over many years. (Health Professional,
38 Paediatric Hospital)
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44 Without any formalised professional routes available, the local, regional and national special
45 interests groups became a central resource for supporting adolescent and young adult health
46 training across the organisations.
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50 At two hospitals, the only initiatives involving training around young people originated from their
51 respective special interest groups, in the form of annual study days. At one of these hospitals, there
52 was a policy initiative explicitly around transition, yet no specific training had been organised. At the
53 other, development of a formal policy was said to be 'not a priority for the organisation'.
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57 Priorities are the front door, A&E [Accident and Emergency], Clinical Decisions Unit, waiting
58 times and, it's those things that they are being judged on.
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2 Interviewer: Why do you think this is not a priority at all?
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5 Just because they've got bigger fish to fry. ... But it's not a priority for the [organization]
6 because of all the other things by which they are measured. And young people's care isn't on
7 that list. (Manager, Adult Hospital)
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11 In the current context of the factors that drove organisational change at this site, creating further
12 engagement and buy-in from senior management were not seen as practical solution. Issues about
13 the care of young people remained focused in the informal, organisation-wide group, of young
14 people's enthusiasts. As we discovered, not everyone interested in the care of young people in that
15 organisation was aware of the existence of that group. Even those within the group were often
16 unaware of the range of young person-orientated initiatives that were occurring within their
17 organisation.
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23 At the remaining hospital specific training around the topic of DAH was observed being planned and
24 delivered. A DAH strategy emerged as the result of the work of key people who sat on a transition
25 strategy group. The group comprised of managers and health professionals, who met bi-monthly.
26 There was strong cross-over between managerial and clinical levels and they worked to actively
27 foster communication and create connections across services. The ideas emerged from the local
28 special interest group, but the dissemination was targeted well beyond that group. Part of this
29 involved looking where change was currently occurring within the organisation, alongside the
30 broader national agendas on young people's health, in order to harness that momentum and get
31 people involved.
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40 The focus of the strategy and training was on organisational level factors (e.g. staff appraisal
41 including training goals around young people; provision of age-banded clinics), clinic and
42 consultation level factors (e.g. signpost sexual health, drug and alcohol services; copying clinic letters
43 to young people), and training and awareness factors (e.g. adolescent development; confidentiality).
44 This programme of training had senior management support, albeit initially only from child health,
45 alongside access to resources. Using money to 'back fill' was seen as a key component in the success
46 of the roll-out of training, as without this departments would not only be unwilling but also unable
47 to release staff for training.
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54 Last year we did, um, we did ten days, so ten individual day sessions for training in
55 adolescent, basic adolescent health. Basically to increase awareness across the
56 [organisation] so as to make sure it wasn't just the, the chronic illness patients that were
57 being looked at ... but it was the patients coming through A&E, coming through X-ray ... just
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to get them aware of what a young person's needs are and why they're different to being an adult (Health Professional, General Hospital).

Central norms and practices of good, everyday, care for young people were distributed well beyond the local existing networks. The initiative emerged from, and depended on, their enthusiasm and expertise. The network of trust of young person-orientated practitioners was then supported by key actors within wider management. This led to an on-going training programme that sought to make the young people's healthcare visible across the organization, to begin to get to people to reappraise values and commitment.

DISCUSSION

Across each organisation a complex, distributed, network of adolescent-oriented practitioners understood the potential value and worth of practices and services for young people, such as DAH. Within and across organisations there is an informal knowledge economy of young people-oriented practitioners, teams and spaces. People have a preference for referring to other young person-orientated practitioners or spaces, to others within their networks of trust. Such referrals help to create, sustain and reinforce the network over time. As such we see evidence of strong communities of practice [29], focused on supporting and enacting adolescent medicine. Table 3 illustrates our results in relation to the four theoretical constructs of normalization process theory (NPT),[21].

Table 3: The four constructs of Normalization Process Theory (NPT) mapped against practitioner groups

NPT Construct	Networks of young person-oriented practitioners and managers	Other practitioners and managers who work with young people
Coherence: Do people make sense of DAH?	See how DAH extends and is related to other approaches to care of young people; relatively shared understanding of purpose of DAH; understanding of impact of DAH on their work; and see potential value and worth of DAH	Diverse views on relationship to other approaches; lack of shared understanding of purpose of DAH; diverse understanding of potential impact of DAH on their work; uncertainty around of potential value and worth (especially, given competing demands)
Cognitive Participation: Do people get involved with providing DAH and stay committed?	They are the key people driving DAH forward; they see DAH as legitimate, generally core, part of role; are very willing to work with others to enable DAH; and motivated to deliver DAH	Aware that key people are driving DAH forward (key young person-orientated practitioners); lack of agreement that DAH legitimate part of work; some are willing to work with others to enable

	over time	DAH; some are motivated to deliver over time
Collective Action: Do people make DAH work in practice?	DAH is operationalisable, especially within network; trust people in network to enact DAH, but less trust beyond; right mix of skills and training to undertake DAH in network, again, less beyond; in one site, clear support for DAH in organisation	Diverse views on workability of DAH and on trust about whether the right people are enacting DAH; lack of skills to undertake DAH, with training offered a one site; in one site, clear support for DAH in organisation
Reflexive Monitoring: Do people evaluate DAH as worthwhile?	Aware of impact of DAH; assess DAH as worthwhile and individually assess DAH as working well; enact DAH flexibly	Unsure of impact of DAH; unsure of whether worthwhile (given competing demands) or working well in practice; may enact some elements of DAH flexibly

The potential for normalization of DAH is high within the group of young person-oriented practitioners and managers, as they make sense of, buy-into, enact, and evaluate it as worthwhile. Beyond the networks of young person-oriented practitioners and managers, we observed a low potential for normalization. There are differences in opinion about the meaning and worth of DAH, its organisational and policy relevance, its potential workability, and its resource and spatial allocation. At one hospital, providing an organisation-wide strategy and training offered a clear opportunity to increase the potential for normalization of DAH. Although not mandated, this programme of training, with support to 'back fill' those attending it, offered the greatest potential for an increase in people seeing (aspects of) DAH as legitimate, to increase buy-in and enrolment. This training has the potential to further extend the networks of young person-oriented practitioners and managers. It relied on buy-in and formal support from senior managers in both child and adult services to initiate and sustain it. The other two sites lacked any formal policy initiatives and any formal support and so had, at the time of fieldwork, a low potential to transform values and commitment across their respective organisations. At the start of the fieldwork, there was no national guidance on DAH. However, since the fieldwork, national guidance on transition [18] states that such care should be developmentally appropriate. This has the potential to enable change. The formal and informal groups with an interest in young people's care at those sites would clearly need buy-in and formal support from senior managers.

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10 This is the first ethnographic study addressing the area of developmentally appropriate health care
11 for young people. This study gathered considerable data from many sources. The focus on exploring
12 the provision of health care for young people over time, within specific teams and specialities, as
13 well as across an organisation, enabled us to demonstrate the diversity within and across
14 professional, team, ward and organisational boundaries. However, we only focused on three
15 different organisations. Notably, all these organisations had a reputation for undertaking research
16 on the care young people, so may represent examples of 'good practice'. Given the timing of our
17 fieldwork, we did not get the opportunity to observe the impact of the roll-out of training around
18 DAH that occurred at the one of the NHS trusts. A potential limitation of the study is that no young
19 people were interviewed. However there is a large literature of young people's experience in
20 hospital settings but much less literature focussing on the perspective of health professionals and
21 particularly of hospital managers.
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32 Policy and research has emphasised the centrality of service delivery and workforce capacity issues
33 to achieve successful integration and consistency of health services for all young people across
34 organisations [8, 9]. The results presented here add to this evidence base as we observed how the
35 community of practice, the networks of young person-orientated practitioners and managers also
36 support and provide, through formal and informal means, training and development around young
37 people's health. Previous research has shown that continuing medical education in adolescent
38 health, can increase developmentally appropriate practices (such as confidential services) and has
39 the potential to address systemic barriers to healthcare for young people.[30] Thus, the role of such
40 networks may be vital to achieving any sustainable change in the provision of healthcare for young
41 people. Across all the sites, young people's formal and informal champions were key to getting
42 people involved in the healthcare of young people. Research has outlined the importance of staff
43 attitudes as a key determinant of young people's satisfaction with care.[4, 31] Prior research has
44 also shown the problem of staff turnover, if services rely on key individuals [32,33] . As such, there
45 needs to be consistency of approach to developing local cultures of good practice that can withstand
46 changes in personnel. In primary care, the Adolescent Champion model, which trains a
47 multidisciplinary team of practice staff to deliver training to other staff and implement local quality
48 improvement, has shown potential for sustainable change [34].
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4 Our findings suggest that there is a need for strong and clear guidelines, strategies and policies on
5 the practical implementation of DAH at three levels: those of the individual young person and their
6 family, the multidisciplinary team level and the organisation and/or system level. Our research
7 informed the development of a toolkit for implementation of DAH at these levels which includes
8 description of the models of good practice in terms of multidisciplinary working and training at the 3
9 hospitals studied [35,36]. Since the fieldwork ended, additional guidance has been published
10 including for the care of young people in acute care settings [37] which includes a focus on DAH,
11 alongside national guidance on the need to implement DAH in relation to transitional care.[18] A
12 focus on specific settings (like acute care) or contexts (like transition) has limitations as it can
13 introduce or sustain inequities. Buy-in and formal support from senior managers in both child and
14 adult services seems essential. Providing an institution-wide strategy and training seems key,
15 particularly in view of the current unmet training needs reported in both paediatric [38] and adult
16 physicians [39]. Currently adolescent and young adult medicine is not a recognised discipline in its
17 own right in the UK unlike Australia and North America [40] although even when it is an established
18 discipline, challenges remain, for example in the USA [41]. The 'informal' adolescent and young adult
19 medicine community in the UK may also need to become more formally recognised. Young people
20 should no longer be seen as 'vary rarely ill' or allowed to remain 'just below the radar', or seen as
21 'too old' for child services or 'too young' for adult. Core principles underlying the practice of
22 adolescent medicine, such as DAH, should not remain contested. We need to enable people to
23 reappraise values and commitment, to understand them as a normal part of everyday service
24 provision.
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Standards for Reporting Qualitative Research (SRQR)*

<http://www.equator-network.org/reporting-guidelines/srqr/>

Page/line no(s).

Title and abstract

<p>Title - Concise description of the nature and topic of the study Identifying the study as qualitative or indicating the approach (e.g., ethnography, grounded theory) or data collection methods (e.g., interview, focus group) is recommended</p>	Page 1
<p>Abstract - Summary of key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results, and conclusions</p>	Page 1

Introduction

<p>Problem formulation - Description and significance of the problem/phenomenon studied; review of relevant theory and empirical work; problem statement</p>	Page 4
<p>Purpose or research question - Purpose of the study and specific objectives or questions</p>	Page 4

Methods

<p>Qualitative approach and research paradigm - Qualitative approach (e.g., ethnography, grounded theory, case study, phenomenology, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g., postpositivist, constructivist/ interpretivist) is also recommended; rationale**</p>	Page 5
<p>Researcher characteristics and reflexivity - Researchers' characteristics that may influence the research, including personal attributes, qualifications/experience, relationship with participants, assumptions, and/or presuppositions; potential or actual interaction between researchers' characteristics and the research questions, approach, methods, results, and/or transferability</p>	Page 5
<p>Context - Setting/site and salient contextual factors; rationale**</p>	Page 5
<p>Sampling strategy - How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g., sampling saturation); rationale**</p>	Page 5
<p>Ethical issues pertaining to human subjects - Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues</p>	Page 5
<p>Data collection methods - Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of sources/methods, and modification of procedures in response to evolving study findings; rationale**</p>	Page 5

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3	Data collection instruments and technologies - Description of instruments (e.g.,	
4	interview guides, questionnaires) and devices (e.g., audio recorders) used for data	
5	collection; if/how the instrument(s) changed over the course of the study	Page 5
6		
7	Units of study - Number and relevant characteristics of participants, documents,	
8	or events included in the study; level of participation (could be reported in results)	Page 6, Table 1
9		
10	Data processing - Methods for processing data prior to and during analysis,	
11	including transcription, data entry, data management and security, verification of	
12	data integrity, data coding, and anonymization/de-identification of excerpts	Page 6
13		
14	Data analysis - Process by which inferences, themes, etc., were identified and	
15	developed, including the researchers involved in data analysis; usually references a	
16	specific paradigm or approach; rationale**	Page 6
17		
18	Techniques to enhance trustworthiness - Techniques to enhance trustworthiness	
19	and credibility of data analysis (e.g., member checking, audit trail, triangulation);	
20	rationale**	Page 6

Results/findings

23	Synthesis and interpretation - Main findings (e.g., interpretations, inferences, and	
24	themes); might include development of a theory or model, or integration with	
25	prior research or theory	Page 6-12
26		
27	Links to empirical data - Evidence (e.g., quotes, field notes, text excerpts,	
28	photographs) to substantiate analytic findings	Page 6-12
29		

Discussion

32	Integration with prior work, implications, transferability, and contribution(s) to	
33	the field - Short summary of main findings; explanation of how findings and	
34	conclusions connect to, support, elaborate on, or challenge conclusions of earlier	
35	scholarship; discussion of scope of application/generalizability; identification of	
36	unique contribution(s) to scholarship in a discipline or field	Page 12-14
37		
38	Limitations - Trustworthiness and limitations of findings	Page 13
39		

Other

42	Conflicts of interest - Potential sources of influence or perceived influence on	
43	study conduct and conclusions; how these were managed	Page 3
44		
45	Funding - Sources of funding and other support; role of funders in data collection,	
46	interpretation, and reporting	Page 3
47		

*The authors created the SRQR by searching the literature to identify guidelines, reporting standards, and critical appraisal criteria for qualitative research; reviewing the reference lists of retrieved sources; and contacting experts to gain feedback. The SRQR aims to improve the transparency of all aspects of qualitative research by providing clear standards for reporting qualitative research.

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**The rationale should briefly discuss the justification for choosing that theory, approach, method, or technique rather than other options available, the assumptions and limitations implicit in those choices, and how those choices influence study conclusions and transferability. As appropriate, the rationale for several items might be discussed together.

Reference:

O'Brien BC, Harris IB, Beckman TJ, Reed DA, Cook DA. **Standards for reporting qualitative research: a synthesis of recommendations.** *Academic Medicine*, Vol. 89, No. 9 / Sept 2014
DOI: 10.1097/ACM.0000000000000388

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