



‘It’s my diabetes’: Co-production in practice with young people in delivering a ‘perfect’ care pathway for diabetes

Darren Sharpe*, Emma Green, Angela Harden – *University of East London, UK*

Rachelle Freer – *NEL Commissioning Support Unit, UK*

Abdul Moodambail – *Barts Health Trust, London, UK*

Steven Towndrow – *National Institute for Health Research (NIHR) Collaboration for Leadership in Applied Health Research and Care (CLAHRC) North Thames, London, UK*

Abstract

This paper considers how young people can help commissioners and providers better understand and address the options and barriers of delivering a perfect care pathway. This applied health study was funded by the National Institute of Health Research (NIHR) in England and a local clinical commissioning group (CCG) responsible for the organization and delivery of NHS services in a socially deprived, ethnically diverse urban locality. The research team was mixed – in terms of age, ethnicity, faith-identities and backgrounds – and worked together over one year to co-produce commissioning guidance. Guidance is intended for use by clinical commissioning groups to support them in commissioning health diabetes services. Our goal was to work with young people to help us understand the options and barriers they face when given a diagnosis of diabetes, and using NHS services. While our NHS partners can provide the latest medical and academic input into managing diabetes, young people have first-hand experience of managing diabetes, the highs and the lows, and only they can provide the inspiration for what would make the service better, now and in the future. With this focus in mind, young people joined the research team to help shape and implement new commissioning guidance. This paper offers the opportunity to reflect on the strengths and weaknesses in involving young people in health service design.

Keywords: user involvement; co-production; learning by doing; peer educators; care pathway

Key messages

- In spite of living with diabetes, young patients have been successfully involved in the co-production of care pathways and provisions for children and young people living in East London.
- The project illustrates how to effectively balance an adult-centric driven agenda to authentically leverage the voices of more 'difficult to engage' or 'vulnerable' groups of children and young people in the commissioning process in order to improve the options, and reduce barriers in delivering a perfect care pathway.
- This project is identified as best practice by the NIHR Central Commissioning Facility (CCF) and NHS England Patient and Public Participation team for its novel way of working with young patients and producing tangible and meaningful outcomes/impact in the field of health service design.

For more information on how to use the young commissioner model to support patient engagement in service transformation/improvements read the How-to Guide (NHS England, 2018).

Background

It's my diabetes (Young panellist at the UCLP- and UEL-organized diabetes event, December 2014).

This paper explores the first phase of an applied health research study to build a shared understanding about the experiences of children and young people using NH diabetes services in London, England to achieve optimal self-care of their condition. The study is led by the University of East London (UEL) in collaboration with a number of other organizations, including a provider of acute hospital services, a health-care commissioning body and a national diabetes charity. Commissioning is the process of planning, agreeing and monitoring services. Commissioning of health services in England has seen significant changes since the implementation of the Health and Social Care Act 2012. The Act puts clinicians in charge of shaping services, enabling NHS funding to be spent more effectively. Previously, clinicians in many areas were frustrated by negotiating with primary care trusts to get the right services for their patients. Supported by the NHS Commissioning Board, new clinical commissioning groups will now directly commission services for their populations. Currently some of the universal health services for children and young people are commissioned by the local authority. In the area we worked in, the local authority did not have the responsibility to commission diabetes services but still collaborated in the project to help improve the health and well-being of local citizens. Given the potential for a number of different providers and commissioners being involved in the organization of services for children and young people, it becomes imperative that a cross-organizational approach was established to ensure they work together in the best interests of those living with, or at risk of, diabetes. A peer educator comments:

What has been positive for me has been the whole journey of learning behind the scenes in what is involved in diabetes health care. Because when you're just a patient, you don't see all the people and organizations that come together to deliver your health care. I thought it was just the

NHS, I didn't know there was such a thing as a CCG [clinical commissioning group]. Now I know this, I thought why shouldn't everybody else know about this too? (Khadija)

Diabetes control in UK children and young people is considered poor when compared with other EU countries, especially in more deprived and at-risk communities. A 2007 Healthcare Commission audit of Primary Care Trusts (PCT) on diabetes care in England found that 26 per cent of all the 'weak' performers in the country were in London (Commission for Healthcare Audit and Inspection, 2007). In the same audit, no London PCTs were rated 'excellent'. London's diverse and mobile population makes delivering diabetes care more challenging than elsewhere in the country. There is a higher proportion of at-risk communities in London than nationally, and these communities are unevenly distributed within London itself. The east of London has a disproportionately high youth population with a prevalence of type 2 diabetes (Balasanthiran *et al.*, 2012), as well as young people with type 1. For prescribing for diabetes in England, spending in East London is the highest in the country, where nearly one in every six pounds (18 per cent) goes on diabetes drugs ('Prescribing for Diabetes, England – 2005/06 to 2015/16' (NHS Digital, 2016)). Subsequently, the research team talked to children and young people living with diabetes, their carers, commissioners and providers (including community pharmacists) to build evidence (Bacchi, 2009) to better understand and address the options and barriers of delivering a perfect care pathway. The young people joined the investigation team – including professionals – as cultural advisers, co-inquirers, diabetes champions and young commissioners. For simplicity, we shall call all the groupings of young people 'peer educators' (Turner and Shepherd, 1999; Campbell and Jovchelovitch, 2000), as they each took on – but not exclusively – health promotion roles in the project (Barnes, 1997). (All quotations from data collection are from peer educators.) Also, for simplicity the paper uses the initialism CYP instead of 'children and young people'. To recap, the paper considers how we can change the way in which diabetes care is offered to CYP, and to raise awareness about the difficulties they experience with current care pathways.

This project is grounded in the idea of co-production to help in the development of diabetes services (Bason, 2010). Co-production is conceptualized here as a method, approach, and mindset to modelling service provision. Co-production is not just a word, it is not just a concept, it is a meeting of minds coming together to find shared solutions (see Gibbons *et al.*, 1994; Callon, 1999; Ramírez, 1999; Dunleavy *et al.*, 2001; Faulkner and Thomas, 2002; Department of Health, 2006; McLaughlin, 2006; Tritter and McCallum, 2006; Staley, 2009; Michels and De Graaf, 2010). In practice, co-production involves people who use services being consulted, included and working together from the start to the end of any project that affects them. When co-production works best, people who use services and carers are valued by organizations as equal partners, can share power and have influence over decisions made. For instance, the NHS and affiliates say:

Co-production not only delivers improved quality, innovation and better outcomes for the individual, the community and the care system – it does so at lower cost (Dineen, 2014).

Taking a co-produced approach to service design, delivery and commissioning can help councils to achieve many of the main principles of the [Care] Act (TLAP, 2014).

The NHS has sought to incorporate expert patients into its model of care since the early 2000s, supporting patient-led research, clinical governance and, most frequently, service design. Although there is still a long way to go, there have been considerable efforts to involve the public. This paper is evidence of how the NHS and CCGs have worked together creatively to involve young people in co-production processes to help improve their understanding about how health and care services interface with the realities of the daily lives of CYP. Accordingly, the drive behind this project was the planned move to community-based integrated care for CYP living with diabetes in parts of London. This move provided a unique opportunity for the research team to make a real difference in strengthening the voices of young patients and their carers in the commissioning process by bringing together patients, citizens, commissioners and providers to deliberate and find common understanding and solutions to designing the ideal care pathway.

The change in the commissioning approach opened up the space not only for patient experience but for peer educators to have a central role in the commissioning cycle. Thus, the research team's guiding principle has been that peer educators had rights to be consulted and involved in decisions that affect their health and care as stipulated in Article 14 of the UN Convention on the Rights of the Child and in the Local Government and Public Involvement in Health Act (2007), which contains the 'duty to involve'. However, we did not want this initiative to be a tokenistic exercise, especially since there is a lack of evidence of the impact/outcome of patient involvement in service transformation and improvement (Armstrong *et al.*, 2013). In the article titled, 'Patients as team members: Opportunities, challenges and paradoxes of including patients in multi-professional healthcare teams', Martin and Finn (2011) highlight how current policy encourages 'partnerships' between users and professionals, so that users, too, effectively become team members. However, Martin and Finn (*ibid.*) also stress how the contribution of service users is more fragile, and open to blurring. Consequently, we planned and tested a model of patient involvement that acknowledged the tensions in sharing power leading to the co-production of knowledge and in decision-making. The following section critically illustrates how young patients living with diabetes played a significant role in the team to address the options and barriers of delivering a perfect care pathway.

Methods

This study is primarily qualitative in orientation and employed an 'action research' approach (Carr and Kemmis, 1986). This methodology allowed for flexibility in the implementation of the research plan to accommodate the voices of multiple stakeholders. Complementary to the principle of action research and a mechanism behind co-production is 'participatory research' (PAR). Participatory research (Cornwall and Jewkes, 1995) is more about how we went about the doing, and draws on the principle of inclusion and the recognition that the power relations embedded in the research process can often disproportionately be placed in the hands of the researcher. Researchers and clinicians alone cannot guarantee improved quality, innovation and better outcomes for the individual. In view of that, this project aimed to lessen these inherent limitations by recruiting peer educators living with diabetes who possessed first-hand knowledge of using local NHS services. However, achieving the commendable goal of integrating peer educators into the project team was not straightforward. A certain amount of capacity building needed to first take place within the participating organizations. Thus, a balance needed to be struck and continually

reviewed between safeguarding against making the act of participation tokenistic and sharing control of the process with peer educators.

In practice, the journey of co-production with a range of organizations and individuals was not a straightforward process and had its own inherent logistical and epistemological challenges. To help navigate our way through these challenges of separating out need from demand and institutional drivers, we applied an analytical framework developed by Hart and Heaver (2012), who convincingly provide a set of ideas and practices in the promotion of CYP's resilience, as well as Robert Putnam's (2000) accepted ideas of social capital and civic community, Jane Foot and Trevor Hopkins's (2010) less well-known ideas of asset-based community development and, finally, Michel Foucault's (1979) recognized work on power and knowledge (detailed later). This theoretical framework helped us to momentarily freeze and juxtapose the peer educator's role operating in a complex system that has historically marginalized the voices of citizens in their own health care (Bochel *et al.*, 2008). The following section details the sequencing and implementation of our action research participatory approach with a specific focus on co-production with the peer educators.

Literature review

The first stage of the research identified suitable existing data sets and other data sources for analysis and synthesis. The systematic literature review of reviews formed one stage in the study design. The peer educators helped to review and refine the exclusion and inclusion criteria. In parallel, the peer educators were also instrumental in translating the emerging findings from the world cafe workshops (see below) to feed directly into the ongoing systematic literature review. The process was iterative, and the peer educators scrutinized the findings from the reviews to inform later research steps (Green *et al.*, in preparation).

Workshops

The world cafe workshop, described by authors as a powerful conversational process for thinking together and creating actionable knowledge (Brown *et al.*, 2010; Sheridan *et al.*, 2010) enabled clinicians, nurses, pharmacists, academics, and CYP and parents (n=45 participants) to hear and learn from one another in two workshops aimed at improving the understanding of the options and barriers, and identifying common solutions to improve local care pathways. Instrumental to this process were the peer educators. The peer educators co-designed the workshop format, and also led in the promotion and recruitment of participants and co-facilitated the events followed by the in-depth analyses of the findings to produce key messages for the multi-stakeholder task group.

Interviews

We used a non-probability sampling frame to identify and recruit potential interviewees from the clinical register held by the local hospital, and identified as 'disengaged' (non-adherence to HbA1c levels and do not turn up to appointments) by the clinician. The age range of interviewees was 10 to 25. They were subsequently invited to take part in the study by a member of their health-care team, followed up by a member of the research team. We interviewed (n=18) CYP living with diabetes, and for interviewees aged under 15 their parents were also invited to sit in. Some parents accepted or joined the interviews at the end, but on the whole most parents declined and interviews were undertaken solely with the youth. The interviews took no longer than one hour

to complete, and were tape-recorded and transcribed in full. The interviewer used a series of age-appropriate consent forms, participant information sheets and interview schedule that was co-produced and piloted by the peer educators. The interviews elicited the subjective accounts of diagnoses and living with diabetes from a child/youth perspective.

Task group

In monthly multi-agency task group meetings, key partners alongside peer educators came together to assess the emerging empirical findings to help inform and shape the next steps in the commissioning process. The meetings served as a space for joint decision-making and to build consensus on key priorities for the commissioning guidance and elements transferable to practice. Data gathered in the workshops and through qualitative interviews underwent first and second level analyses with the help of peer educators. They in turn co-presented emerging findings to the task group. The research team used a thematic approach advocated by Miles and Huberman (1994: 10–12) that sets out how thematic analysis should emphasize patterns that occur across data sets, which contribute to the description, in this case, of options and barriers of delivering a perfect care pathway (Braun and Clarke, 2006).

Results

This section now turns to discuss the implications for service redesign of involving young patients in research processes designed to inform service transformation (McNeish and Newman, 2002). The peer educators were invited to be involved in the study for its duration, with the caveat that they could exit and re-enter at different points of the study to fit involvement around their work, training, education and family commitments (Sharpe, 2012). We also used a mixed-remuneration approach to compensate the peer educators for their time and travel on the study. For instance, we had both paid (cash) and unpaid (vouchers) positions, and we covered all travel expenses and always provided an assortment of refreshment to ensure that the peer educators' sugar levels were stable so they could perform at their best. The peer educators (aged 17 to 25) were recruited between January and April 2015, and were trained and supported to activate their experience and knowledge of diabetes disease and diabetes services. Our presumption was that the peer educators would provide insider knowledge of where CYP are dissatisfied with local efforts. The peer educators were much closer culturally, geographically and by age to the sample population under investigation than the adult members of the research team, and therefore helped team members to bridge differences in meaning and interpretation of local NHS services.

In total, 40 young people responded to the study call to become peer educators (for example, young commissioners, young researchers, cultural advisors and a youth champion). The group consisted of 49 per cent (N=19) female and 51 per cent (N=20) male. The majority, 65 per cent (N=26), were not accepted on to the study for a variety of reasons. From the group who were accepted, only 2.5 per cent (N=1) joined the study midway into the programme, and from the pool of peer educators who started from the outset, 22.5 per cent (N=9) stayed for the duration, and the rest, 10 per cent (N=4), did not complete due to transitions into higher education outside of London. The peer educators all had knowledge or experience of diabetes, and contributed to the refinement of the research tools, youth-proofed consent forms, and participant information sheets, scrutinized the NHS ethics application, piloted the

interviews, and co-designed and led in the delivery of the world cafe workshop series and helped in the interpretation and analysis of data leading to the production of new commissioning guidance. The peer educators were provided with training, and supported by a dedicated team made up of University staff, the NHS Transforming Services Together team and the CLARHC North Thames PPI Officer to competently and confidently undertake the aforementioned tasks. The peer educators comment:

I think the training helped to make sure I knew what to do. So every time I go out somewhere, I run the training sessions through my head. We had training and I'm not afraid to ask questions anymore (Shandies).

What has been positive for me has been the whole journey of learning behind the scenes. Because when you're just a patient, you don't see all the people and organizations that come together to purchase and deliver health care (Harmeet).

I think this [experience] actually did help boost my confidence. Not just working on this project, but like in other areas of my life (Kadesh).

The most significant piece of work undertaken by the peer educators was the co-production of the commissioning guidance. In order to do this task, the peer educators co-designed and ran a series of world cafe workshops, where they facilitated group discussions to generate detailed information from CYP living with diabetes, their families and health-care workers on how they would like to see services changed. This information was then thematically analysed by the peer educators before being shared with the multi-agency task group. Members of the task group collaborated with the peer educators in a prioritization workshop and using a matrix set the key priorities that would appear in the 'intention letter' (that is, market position statement), which sat behind the commissioning guidance for 2016/17. What is more, the task group with the peer educators' helped identify common concerns that could be adopted straight into practice. There is no space to go into the steps taken here, however due to the peer educators' knowledge of local services (for example, as end users), they were adept at contextualizing and prioritizing the most relevant issues, although they needed additional support to confidently speak out on some matters that concerned them. The peer educators commented: 'I'm not afraid to ask questions anymore' (Shandies).

The main findings of the co-production process are discussed below. The key points that were adopted into the commissioning guidance, translated straight into practice or parked for a later stage in the commissioning cycle are shown in Table 1.

Table 1: Key points of the co-production process

1. Relationship with health-care team	Private appointments (for example, written into the commissioning guidance)
	Three-way relationship and communication (for example, translated into practice)
2. Clinic appointments	Timing (availability) (for example, no steps taken)
	Virtual clinics (for example, translated into practice)

3. Transitions	Gradual process (for example, written into commissioning guidance)
	Co-designed personal plan (for example, translated into practice)
4. Peer support and self-care	Mentor/buddy scheme (for example, no steps taken)
	Reducing stigma (for example, translated into practice)

In connection to virtual appointments or consultations (Greenhalgh *et al.*, 2016), the peer educators recommended that the NHS issue laptops for patients doing well in maintaining their HbA1c levels to allow them easy access to information, and also to schedule appointments with their clinician and/or nurse so that they are always on top of their diabetes self-care. The idea of issuing patients a laptop was considered a financial impasse by some of the health professionals on the task group. Other task group members sided with the peer educators and thought that the upfront spending could create cost savings in the long term – in the reduction in missed appointments (DNA), diabetic ketoacidosis (DKA) and A & E admissions. Two other episodes stand out as barriers where the peer educators were challenged by adult members of the task group on their ideas. The first instance was the peer educators' request to paint the waiting room wall(s) in the newly located diabetes community clinic based in an old Victorian site. The diabetes clinic shared the space and equipment with a tuberculosis outpatient clinic. Ideally, the peer educators would have liked to have access to Wi-Fi in the waiting room area, designated consultation rooms grouped together and better quality measurement equipment. However, with a limited budget and realistic expectations, the peer educators settled on a facelift for the waiting room area, but were told 'no' by a senior health provider to painting the waiting room wall any colour other than white because it might cause offence to adult patients. This was dealt with as a binary choice of a 'yes' or 'no' answer with no other alternatives.

Likewise, following a lengthy period of consultation and co-production, the peer educators were dissatisfied when their work in designing a diabetes care plan and diabetes passport – supporting a smooth transition between services – was superseded by a more comprehensive care plan designed by the same health-care worker who had assisted them in the co-produced plan. When questioned about the duplication in output and apparent marginalization of their voices, the health-care worker revealed the transition plan they had submitted for approval was designed with the health professional in mind, although it had always been sold as a tool to promote inclusion of young patients in their own care. This mismatch in expectations in the co-production process exposed the potential for tokenism when working with peer educators who had continued to be labelled as disengaged on the basis of the health workers' background knowledge of their HbA1c levels, which scored below the national target of 7.5 per cent. It transpired that they were being perceived by the nurse as not deserving of having a voice in the redesign process on the basis that they could not care for themselves and therefore could not speak on behalf of others. These examples were the exception, and on the whole the task group created the right set of conditions for peer educators to be heard and supported to act as role models in the local community. The seven key conditions for this are:

- pre- and post-task-group meeting briefings
- all the peer educators invited to attend each of the task group meetings
- training in how to participate and in formal procedures of multi-agency meetings
- site visits to each of the multi-agency sites to build familiarity and understanding
- young-people-friendly times and dates to hold task group meetings
- being challenged and prized in equal measure
- prerequisite for effective partnership working is collaboration, inclusion and respect.

Despite being openly challenged, the peer educators did not communicate that they felt beaten and retained their motivation and focus to try and improve the care pathway. The peer educators comment:

The work I've done is great, but I think I just kind of hoped we'd be able to take it a bit further. I would have liked to have engaged with people higher up, people who actually have the power to make the changes and help those living with the condition (Kadesh).

You could definitely feel sometimes as though you were like the child in the room. When you're in the room with the other commissioners you are definitely not treated differently, but it's not the same. We do get respect, and we do get responsibility, but I would like more (Tahimd).

The work undertaken by the peer educators has contributed to the rethinking of the locality's whole-system approach in treating childhood and youth diabetes as it relates to aligning paediatric and adult care pathways and creating fairer access to local services, coupled with understanding how complex systems (for example, home, school and leisure) impact on CYP's self-care. In terms of participatory action research that informed the decision-making processes, the empirical data has built local intelligence for the commissioners and providers to better understand the significances of: transitioning between services for young people and informed the transition plan being piloted in the local paediatric hospital service; the London Healthier Partnership Transitions Service Specifications; and also informed the development of the NICE guidelines for children and young adults diabetes services, 2016.

Discussion

We report here the advantages and limitations of peer educators' involvement in decision-making processes. The NHS aspires to carry out a five-year programme of transformation of services with the involvement of patients to produce cost-effective and quality services to meet patients' needs. This will be done by breaking free from simply surveying and consulting patients, and moving arguably towards a bottom-up and top-down approach (that is, vertical and horizontal dialogue) to find creative solutions. In this study, the commissioners, providers and young patients spent time talking and listening to each other, which revealed a co-imbrication in ideas. It is too early to say that we will see through the active involvement of young people in the commissioning process reductions in diabetic ketoacidosis (DKA), missed appointments (DNAs) and overnight stays in hospital, and improved HbA1c levels. However, meeting regularly for short learning sessions, the peer educators improved the reliability in the data by grounding emerging theoretical presumptions in youth practices, which built robustness in the study and commissioning cycle.

Most, if not all, of the adult members of the study team started with the presumption that the peer educators would possess certain skills and assets acquired through their regular negotiation and navigation of NHS services. As a consequence, the study team conceptualized peer educators as 'experts by experience' (Kennedy, 2003), even if they did not see this initially for themselves. The presumption was that young patients would come with skill sets and assets acquired over time through reciprocal relationships experienced in the community, at home and through exposure to health-care teams. These skills and assets are essential to how young patients build liveable lives with a chronic illness. This observable fact can be theorized partially through the 'resilience framework' (Hart and Heaver, 2012) to show how self-confidence and self-advocacy should be nurtured in patients (with the help of other diabetics and non-diabetics), leading to improvements in self-care and well-being. Also, the idea of 'social capital' (see Bourdieu, 1986; Putnam, 1995) provides a useful way to frame how peer educators might activate and mobilize their assets to influence the direction of the commissioning process. Social capital for many thinkers rests within networks of interest that are cultivated in bonds of common interest (for example, class, ethnicity, religious loyalties and geographic locations). The theorists Granovetter (1973) and Putnam (2000) found that the quality of social networks can be more important than the quantity. In this sense, Putnam (2000) also differentiates between 'bonding' and 'bridging' social capital: bonding social capital supports solidarity within existing tighter groups, whereas bridging social capital creates new chances beyond their own groups, due to its relations between individuals who occupy distant social positions. This work has been focused on how to bridge the peer educators' bonds and build new relationships within the health-care community. Take, for instance, the accounts of peer educators:

My relationship with the health-care team has really improved. My doctor emailed me yesterday saying if I needed any help with my career plans. This is because we were speaking about my university options. The exchange did not have to do with my diabetes, we were just talking like colleagues or friends – which is very nice (Thamid).

You know that there are people out there trying to support you who are willing to help (Shandies).

Putnam (2000) advances our understanding of what occurred in his description of bonding and bridging social capital, which can lead to collective action for the common good, demonstrated here in how the peer educators connected with new groups to advocate for other CYP living with diabetes.

However, Foucault (1979) reminds the reader that power relations and techniques (such as diagnosing and treating disease) mediate all social relations and institutions, and serve to maintain the status quo. For example, the 'medical model' inherent in most NHS service delivery models emphasizes the 'disease' and not the 'illness', and patients are often considered by practitioners in paternalistic, inhumane and reductionist ways. What is more, young patients are often locked in an intersectionality of marginalization as a result of their age and 'disease' and, as a cause or effect, often perceived by the medical community in normative terms of compliance and vulnerability. This project departed from this way of seeing, and placed peer educators' interpretation and emotions of living with diabetes on a par with clinical knowledge of the treatment of diabetes (Mol, 2002: 9). In the study, the adoption of an asset-based

approach (Foot and Hopkins, 2010) recognized not only how peer educators can help refine NHS services, but also bring a unique perspective to researching CYP lives.

Limitations

As previously alluded to, power mediates all health relationships, and relations in applied health research is no exception (see Hill *et al.*, 2004; Spyrou, 2011). For instance, in planning for research Franks (2011) notes how the power of the research process itself can inadvertently create a barrier and exclude young people from taking part through its highly structured language and the complexity of research procedure. Not only are budget holders responsible for this, but Morrow (2008) notes how the fault also lies with the adult researchers as they often make the crucial decision of which methodological approach to use in research, which the young people as co-inquirers will have to foster. In the same vein, Kellett (2010) agrees that knowledge is power, and the lack of knowledge and research skills can be a barrier for CYP involvement in research. However, this could be the same for any adult undertaking applied health research without some form of training. Skelton (2008) highlights oppressive power relations in society – age difference being a marker of power – which can be reproduced in the research environment. An exemplifier of this is the power differences even among CYP in the different groups ascribed to them (such as social class, age group, linguistic skill, physical ability or popularity).

To address these concerns, the research team and commissioning body planned for CYP involvement from the outset. We recruited CYP living with diabetes to draw on their expert knowledge and selected a participatory methodology to ensure we balanced participation with rigorous data collection that could feed into a real-world process of change. We involved CYP in decision-making, and were upfront about where adults would lead. Despite the fact that the very experience of real decision-making and taking responsibility inherently carries with it certain risks, it can also heal 'low self-esteem' and 'feelings of powerlessness' (Stoneman, 2002: 221, 226) and bring about the feeling of 'dignity'. Peer educators' competencies and responsibilities for decision-making in this applied study reveal the challenges on one level for achieving rights-respecting research (see Alderson, 2012), and on another level the sociocultural and socio-economic conditions to enable active participation. To summarize, meeting peer educators as knowledgeable agents involved having the right culture, structures and systems in place in order to facilitate safe, respectful and authentic dialogue for change. For instance, we built on the culture of interagency partnerships, which promotes inclusiveness and shared understanding; youth-proofed structures that can sometimes hinder rather than support involvement; and, finally, capacity-building to ensure we had agile human resource systems in place that afforded peer educators employee protection but at the same time recognized their precarious status. Our goal in this NHS youth forum space was to make the experience accessible, relevant and fun for peer educators in order to gain and sustain their cooperation and enthusiasm. All our steps and actions taken focused on the empowerment of young patients to have their voices heard in the commissioning process, without undermining the integrity of health services.

Policy practice and conclusion

This study worked together with young patients to transform local health diabetes services. By the end of the first phase, the peer educators had influenced and positively

impacted on the commissioning process as part of the research process and in shaping the guidance instructions. All the peer educators demonstrated increased confidence in their role, as they became more knowledgeable about the commissioning cycle and overcame the awkwardness of being challenged and challenging the decisions of commissioners, providers and researchers. One peer educator comments, 'I think this [experience] actually did help boost my confidence. Not just working on this project, but in other areas of my life.' The project effectively balanced an adult-centric driven agenda to authentically leverage the voices of CYP in the commissioning process to improve the options, and reduce barriers, in delivering a perfect care pathway.

This study has tested the values and principles of joint working by local NHS providers and commissioners with young patients. The study has involved young people as trained peer educators. It has validated options such as the offer of virtual appointments and piloted outpatient clinics that together demonstrate how the NHS should be more flexible and provide options within a care pathway that meet the range in needs of young patients who balance their condition with education, work, sports, friends and family dynamics during a period of both physiological and psychosocial change. Access to age-appropriate and timely health services is just one feature addressed in this study that can be strengthened still further by routine intergenerational dialogue with young patients as part of the commissioning cycle, as modelled here. This approach to engage young people in health service design was highly valued by the partnering organizations, and can be applied elsewhere in health-care settings where CYP are important stakeholders:

When I go for a job in the future, I think I'll be much more equipped and know what to expect (Kadesh).

I still want to make more changes. There is another year to go on the project where we might be able to do this. Maybe next year we'll be able to tackle those and other issues (Tahmid).

Declarations

The study gained ethical approval from NRES Committee South East Coast, Surrey Research Ethics Committee and the University of East London Research Ethics Committees (UREC). In this paper, confidentiality of personal data has been protected through the use of anonymization and pseudonymization.

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Notes on the contributors

Darren Sharpe is a consulting sociologist in the public care sector based at the Institute for Health and Human Development at the University of East London. Darren leads the NIHR North Thames CLAHRC-funded study modelling community-based diabetes services for children and young people. Darren is also an internationally recognized expert in participatory research with children and young people.

Emma Green is a PhD student at the Institute for Health and Human Development, funded by the NIHR CLAHRC North Thames. Emma's doctoral studies examine an asset-based approach to the management of diabetes in young people.

Angela Harden is the Director of the Institute for Health and Human Development based at the University of East London and is a professor of community and family health. She is currently leading work on new models of antenatal care, addressing low birth weight and community-centred approaches to promoting health and well-being. Angela is also an internationally recognized expert on systematic reviews and evidence synthesis.

Rachelle Ferrer was previously a junior consultant based at NEL Healthcare Consulting – a consultancy by and for the NHS. Rachelle is expert in delivering, supporting and advising complex programmes with different partners and stakeholders across multiple organizations. Rachelle is now a youth engagement trainer consultant with Young Minds, focusing on improving young people's mental health and well-being.

Abdul R. Moodambail is a consultant at Barts Health NHS Trust and a senior lecturer at Queen Mary University London. At Barts Hospital, Abdul leads the paediatrics diabetes team, and also works closely with primary teams to deliver diabetes care for children and young people with complex diabetes-related problems.

Steven Towndrow is the Patient and Public Involvement/Engagement and Communications Officer based at the National Institute for Health Research (NIHR) Collaborations for Leadership in Applied Health Research and Care (CLAHRCs) North Thames. He previously worked at Guy's and St Thomas' NHS Foundation Trust on their Patient Experience team and for Westminster Local Involvement Network (LINK) as Policy, Engagement and Communications Officer.

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