

**TOGETHER study:
Co-designing group clinics for
young adults with diabetes**

Year 1 report

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The Association for Young People's Health

AYPH is the UK's independent voice for youth health. We bridge the worlds of policy, practice and evidence to promote better understanding of young people's health needs. We support the development of youth friendly health services and believe these should be evidence-informed. We undertake projects that facilitate more effective communication between practitioners, raise the profile and understanding of young people's health needs, test out new ways of working, and ensure that young people's involvement is central to service development.

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Executive summary

- Young people with diabetes often have their medical care delivered in 1-to-1 appointments with health professionals. Recent research has suggested that ‘group clinics’ may be a better way to engage young people and offer them medical care.
- Using a streamlined version of the Evidence-based Co-design process, young people with diabetes and staff at Barts Health NHS Trust were involved in discussing possibilities and issues in the development of a new group clinics model.
- The process involved separate and joint discussions for patients (young people) and staff, facilitated by the Association for Young People’s Health.
- There was agreement that a group clinic is a good idea for educating young people about diabetes and reducing feelings of isolation, particularly in local communities.
- For both patients and staff the key issues centred around understanding the role of group clinics, the possible content, a range of practicalities, the challenge of engagement, and the relationship with individual consultant/nurse 1:2:1 sessions. The staff group also raised some additional issues from the perspective of NHS provision and the need to consider what ‘good outcomes’ looked like, and how these would inform commissioners.
- The sessions also revealed a collective view that while the right format for the clinics was not immediately clear, it should emerge through the process of implementation. The project evaluation would be an important way of recording the conclusions about how best to ‘form’ the groups, and how best to organise content and facilitate the sessions.

1 Background

Young people with diabetes

Diabetes is a serious life-long health condition, where the amount of glucose in the blood is too high because the body cannot use it properly. It may cause longterm complications and needs to be well managed. Significant numbers of young people live with diabetes in the UK. Drawing on surveys from England, Wales and Scotland, the charity Diabetes UK has estimated that there are approximately 31,500 children and young people under the age of 19 who have diabetes. On this basis, Diabetes UK estimates that local authorities can expect between 100-150 young people under 18 to be living with diabetes in their area.

31,500 children and young people under the age of 19 have diabetes in the UK

Peak age for diagnosis of **Type 1 diabetes** is between 10 and 14



Similar estimates of prevalence are provided in an annual national paediatric audit undertaken by the Royal College of Paediatrics and Child Health (RCPCH 2017). The 2015/16 audit included all 173 paediatric diabetic units in England and Wales and collected data on 28,439 children and young people up to the age of 24 years under the care of a paediatric consultant (all young people with diabetes should be under the care of a consultant but some may not).

The great majority of these young people (95%) have Type 1 diabetes (Diabetes UK, 2016). The peak age for diagnosis of Type 1 diabetes is between 10 and 14 years of age. Although Type 2 is rare in young people, it is known to be nine times more common in children of South Asian origin than white children, and six times more likely in African Caribbean children. It is thus particularly an issue in areas of the UK with higher proportions of these ethnic groups, including (in the case of this study) some London boroughs with a deprived and ethnically diverse population with a high prevalence of long-term conditions and reduced life expectancy compared with UK averages.

Supporting people with diabetes to self-manage their condition is the cornerstone of good diabetes care. Management of diabetes in young people can present challenges. All those over 12 years should have certain checks that are required to screen for various complications arising from the disease. In the 2015/16 audit, only two thirds of young people aged 12 and above had the required foot check, a retinopathy screen or urinary albumin recorded. It was noted that children with Type 1 diabetes had worse diabetic control if they lived in a deprived area, were of a non-white ethnicity, or were female (RCPCH, 2017). Indicators of complications were found in significant proportions. Older young people with Type 1 diabetes were at increased risk of eye disease, with 20.5% of 17 year olds screened having an abnormal result. Macrovascular complications and high cholesterol levels were also recorded in significant proportions. These findings suggest that age-appropriate interventions are required to target better diabetes control in young people. The experience of living with diabetes while making the transition to adulthood can be a challenging one that may require specific, youth-friendly provision.

Young people with diabetes often have their medical care delivered in 1-to-1 appointments with health professionals. Recent research has suggested that 'group clinics' may be a better way to engage young people and offer them medical care (Raymond et al, 2015; Floyd et al, 2016). The 'TOGETHER' study is testing a 'group clinic' model for young people with diabetes in Newham, to see whether this could improve their health outcomes and, if so, how and why groups achieve this (Papoutsi et al, 2017). The intention is to develop the group clinics as a way of promoting better self-management, not simply improving diabetes education. The project is funded by the NHS National Institute for Health Research, and involves a team of researchers, clinicians, and youth participation experts.

Co-designing health services with young people

A key feature of the TOGETHER project is that the service is being designed in partnership with young people and staff. The last decade has seen increased emphasis on the importance of patient involvement in services design in the NHS. Research suggests that co-designed services can lead to service improvement (Locock et al, 2014a; Locock et al, 2014b;

Steen et al 2011), but also that the process can bring challenges relating to the relationships of power between patients and public services (Donetto et al, 2015).

Various models of co-design have several common features. Co-design focuses on understanding and improving patient and staff experiences with both activities being seen as equally important. New services, or changes to old services, are made together, based on an equal relationship throughout the process. The emphasis is on participants being 'expert through experience'. Patients and staff are encouraged to express emotions and experiences, rather than attitudes and opinions. These are shared through informal discussions and storytelling to identify opportunities for improvement and adaptations to service design – focused on the functionality (usability) for patients and staff. In co-design approaches, patients and staff work alongside each other to identify problems that can be practically overcome and to develop a jointly negotiated outcome.

There are particular considerations in co-designing with young people, requiring special facilitation skills and potential modifications to usual procedure. The role of the facilitator is key in building trust (Donetto et al 2014), but there are also considerations around the special challenges of engaging young people to take part, and in ensuring informed consent. In developing the co-design process for this project we drew on the first stage of the TOGETHER literature review on group clinics for young people. This provided a range of considerations that provided useful areas for discussion, including the following issues:

- **Group composition and continuity.** There is little certainty in the literature around the best mixture of people to involve in group clinics. Groups might be based on age-related developmental stages, on gender, or on disease type. Other considerations include levels of independence, time from diagnosis, family circumstances and general life experiences. The literature did stress that group continuity was important for bonding, cohesion and sharing of stories, but there were no clear messages on how this could be achieved.
- **Role of parents.** The research literature identified parents as possible active participants, whose attendance could have a mixed effect.
- **Individual versus collective experiences.** The research literature raised the issue of managing discussion in groups to cover different interests as well as shared experiences.
- **Content and approach specific to young people.** The literature suggested that many young people prioritised fitting in with their peers rather than closely observing diabetes management. Addressing topics that played to this tendency may increase group coherence.
- **Practical considerations.** A wide range of practical considerations for group clinics were raised in the literature including scheduling, whether groups were alternatives to other kinds of appointments or in addition to them, how the group should be led and facilitated, how frequently they should be held, how ground rules were established, and other issues.

2 The TOGETHER project co-design process

An outline of the process

The co-design process used in the TOGETHER project was based on the King's Fund 'Experience-based Co-design toolkit' (Kings Fund 2013; Bowen et al 2013; Donetto et al 2015). The Experience-based Co-design process provides a template for co-designing service development drawing on the expertise of patients and staff, with regular review and iteration. The approach is qualitative, not quantitative, and gives a rich insight into the experience of all participants, both patients and staff. By documenting (via recording, film, audio etc.) each group, and then bringing the insights and groups together, it is possible to prioritise areas for improvement, define key actions, focus outcomes and broadens understanding of stakeholders.

The co-design process has evolved and been adapted as the project has developed. Of necessity it has had to fit around availability of participants, constraints of practicality, and hospital procedures. There are particular challenges of engaging young people in co-production work, especially if they are also coping with a long-term condition and the day to day challenges of education and/or work. As a result, a streamlined version of the full procedure was employed. The key elements and milestones included:

- **Interviews and group sessions** separately with young people and staff
- **Analysis of main themes** arising from the interviews
- **Joint patient and staff event**, to bring perspectives together
- **Further analysis** of emerging themes
- **Follow up interviews** with additional participants
- **More joint groups** as necessary to agree out the finer points of service design and delivery
- **Celebration event** for co-production participants as the new service commences

The full Experience based Co-design process includes the production of a series of films that help to share perspectives between the groups. However the adapted approach taken in the TOGETHER project did not include the filming elements, for reasons of resource and practicality. This is a common issue and more streamlined versions of the Experience based Co-design process are being developed that draw on pre-existing filmed material (Locock et al, 2014b). The particular challenge of working with young people and needing the material to be directly relevant to them, together with resource and time constraints, meant that using pre-existing films was not an option open to us at the time of the project. We relied instead on audio taping and verbal feedback at the joint meetings. Co-design workshops took place in community-based facilities in the London Borough of Newham. The co-design was also informed by a parallel theory-driven, realist review of the literature (Papoutsi et al, 2017), and in turn the results of the co-design are feeding back into the review.

The co-design process required the input of a number of people across the research team. The key team members included:

- AYPH – external team of co-design facilitators, with particular expertise in participation work with young people and health professionals
- Service delivery team – consultants, nurse specialists, reception staff
- Project management team – NIHR investigators, administrators
- Researcher in residence – an embedded researcher who bridges the qualitative and quantitative parts of the evaluation, helping to include practitioner & patient views into the design.

This report presents the results from the first phase of co-design in the spring and summer of 2017, but a second round in 2018 will further develop the group clinic model.

Consent/information procedures

Participants were identified by the diabetes service at Barts Health NHS Trust (Newham University Hospital). Different and appropriate information was given to the young people and the health professionals. Written information was given in advance of sessions, explaining the study and what participation in co-design would involve. As well as ensuring informed consent, this helped to get thought processes started prior to the sessions, and to lower any possible anxieties people may have had. The co-design received formal ethics approval (IRAS:212811 Rec Ref: 17/NI/0019) as part of the larger research programme.

Preparations for groups and individual interviews

We spent some time preparing for the co-production sessions. This included articulating the philosophy behind the process, drawing on considerations from the literature review that fed into the co-design process, discussions at the Project Steering Group, specific co-design teleconferences with TOGETHER team members, drawing up protocols for the groups and interviews, securing transcription services, and confirming procedures for consent.

Participation by young people

Each individual was encouraged to tell their own story, recalling their own voice and experiences – communicating their own personal ‘truths’. The facilitator had prepared a workshop of questions and workshop activities to defuse any anxiety or embarrassment and provide a way to encourage sharing. However the issues raised mainly came from the participants, and discussions followed the line they wanted to take. Sessions lasted no longer than two hours and opened and ended with a ‘check-in’ to raise any emotional anxieties and to ensure young people left the process in a safe state of mind, feeling supported, and listened to. Young people were also given an outline of the next steps in the work and details about how to find further information.

It proved challenging to engage young people. The young people living with diabetes all led particularly busy lives. Several expressed an interest in taking part in the co-production, while talking on the phone, via Whatsapp, text message or face to face, but seemed to lose interest when following up to confirm dates and details. After a lot of chasing, the young people who then did not take part seemed to do so because of educational commitments, or because they needed to help out at home caring for younger siblings.

Many of the young people who were interviewed arrived late or were limited to a short amount of time. This was due to family or work commitments. One young man was 45 minutes late because he was with his mother in hospital, waiting for her appointment and didn't want to leave her waiting by herself. Another young woman left early to pick up her younger sibling from school. Six sessions were planned and four took place, including two females aged 18, a female aged 20 and a young man aged 24. All had diabetes, but they were not asked what type by the facilitator. Information is on their consent forms and can be acquired.

Staff sessions

It was important to allow staff the same freedom as the patients to express their stories and their truths, should they need to. Two staff sessions took place, one at the Shrewsbury Health Centre, and one at Newham Hospital. Participants included a wide range of professionals and stakeholders including dieticians, specialist nursing staff, a CCG commissioner, representatives from primary care, representatives from the voluntary sector (Diabetes UK), consultant diabetologists, and reception staff. The sessions were audiotaped and transcribed.

Joint discussion

Originally the plan had been to stagger young people and staff sessions, have a period for reflection, and then hold a joint session, but practicalities meant that several of the groups occurred very close together over a 24 hour period, consisting of one staff group, one young people session and a second staff group held concurrently, then a joint session. For the joint session the professionals and the service users had separately prepared three issues to present to the other group and wide ranging discussion ensued.

This allowed less time than planned for collating and sharing the perspectives of the young people with the staff, but the preparation of the three key issues from both sides provided a useful structure for the joint discussion on ways forward.

3 Themes from separate co-design sessions

For both patients and staff the key issues centred around understanding the role of group clinics, the possible content, a range of practicalities, the challenge of engagement, and the relationship with individual consultant/nurse 1:2:1 sessions. The staff group also raised some additional issues from the perspective of NHS provision and the need to consider what 'good outcomes' looked like.

Young people sessions

All young people interviewed in the co-production process felt that a group clinic was a good idea and would be useful for most young people. The objectives needed to be clear, however, as they would not be able to invest without understanding what they were going to get out of it. Below is an outline of the main issues discussed by the young people.

- **Role of group clinic**, covered a range of issues, including:
 - **Promoting healthy behaviour:** Generally it was felt that a group clinic could work well as an educational programme, to help young people gain knowledge about their condition and promote a healthier lifestyle by sharing: *"You also learn from other people's mistakes and how people are doing good, kind of coping with the diabetes. I think that's probably a good aspect of the group clinic."*
 - **Promoting confidence:** Most of the young people recognised that some group members may not be vocal or confident about voicing their concerns around health or personal issues, and that a group may help them with confidence issues: *"I guess you could learn from each other as well. So if someone brings up a question that you might have wanted to ask, but you were maybe shy to ask"*.
 - **Reducing isolation.** Being a young person with diabetes can be isolating and clinics could help with this. As one said, *"I've had diabetes for five years but as a young person I didn't know any other young person with diabetes... when you first find out (you have diabetes), for young people they don't know anyone and they feel like it's just them and they're alone"*.
- **Suggestions around practicalities:** These comments centred on timing, group numbers, age and gender.
 - **Timing:** A unanimous conclusion from the young people is that Saturday morning, or any morning, would be an inappropriate time to try and engage young people. All members of the discussions felt a week day evening, after work or college was the most likely time to get young people to attend, *"if people are already out, you're more inclined to say, after I've finished this, I'll*

just head there and do that (group clinic)." Awareness of timing of cultural events such as Ramadan were also important.

- **Numbers:** The young people all agreed that the groups would work with maximum numbers between 7 and 10. The lowest minimum group number suggested was three.
- **Age:** Age turned out to be one of the most divisive factors in the co-production interviews. Some felt that all groups should be similar in age; others saw the advantage of a mix. *"there's two ways you could look at it, if everyone was the same age it would be good in terms of them being able to know each other and relate to each other more and speak to a practitioner, but if everyone was different ages, it would be kind of like a mentor-ish kind of thing"*
- **Gender:** No young person we met felt that the gender of the group mattered to them personally. However they did say that some young people may want specific gendered sessions, depending either on personal preference or the nature of the topic being discussed. None suggested that cultural differences would be a factor in a gender divide.
- **What the space looks like:** The young people were keen on a room that would be welcoming and friendly, but not childish, *"Nothing bland, first thing I would want to see is bright colours, eye-catching colours. It just makes it more friendly, posters and whatever it is, but then again some people wouldn't like that, they feel like it's too childish. So maybe like a neutral colour. Just something that grabs their attention, makes it feel friendly"*. Ideally there would be a way of passing time while you were waiting; *"...if they had, like, pool tables there, and other stuff, like an arcade.... That way, when you come in and you see your clinician, be it a group or whatever, you could go and play with the group afterwards, and that way you're building a bond between the group as well, and it's kind of an incentive to go as well."*
- **Considerations for content:** The young people were keen to talk about more general issues associated with diabetes, including things that affected their lives outside of their medical or clinical experience. It was felt that the clinics should take on a holistic approach, addressing emotional and social aspects of health issues, for which peers may be better informants *"It's not only a Q n A towards the healthcare professional, it's also each other, because young people are the experts, and the healthcare professionals, most of the time they don't have the condition, they're not the same age, they don't live with it. We can ask each other how we handle certain things."* Content may also be affected by the type of diabetes young people had: *"The difference between type one and type two diabetes is too big to have one group"* *"Type 1 and 2: so you probably would have to have two separate groups for that."*
- **People in attendance.** All young adults wanted the group to be a 'parent free zone', however several alternative suggestions were made, such as a separate group for parents, an open day for parents to attend and hear about the groups, or an

education day for parents to learn more about the concerns of young people with diabetes. As one commented, “... *it’s always good to have your parents’ support, so they support you with any problems you have with the diabetes, but I think it’s a learning curve in itself really. I think when you’re younger, it helps with your parents’ support, but when you’re a teenager going into your twenties, I think it’s all about learning yourself.*” Some of the participants also observed that a skilled youth worker could act as an advocate for young people and bring a level of skill in communicating and engaging with young people.

- **Style of delivery:** All felt that a Q&A style session would be useful. However young people were more concerned with the tone of the group than delivery style or content. They did not want to be made to feel shame or embarrassment if they were not managing their condition well. In order for young people to turn up and be open and honest about their condition the group needs to be a non-judgemental environment, a place where they can talk about what is going well and what they are struggling with that is confidential and safe: “*most times when young people aren’t coming to clinics with healthcare professionals, they are scared. When they know they haven’t been taking care of their condition, most don’t turn up because they are running away.*”
- **Challenge of securing commitment** The participants were unanimous in their agreement about how difficult it would be to engage young people on a regular basis. Reasons given for young people’s lack of engagement all revolved around the busy and sometimes hectic lives young people can lead, “*their head’s all over the place with exams and schooling, diabetes shouldn’t take a back seat but it usually does*”. Attendance would be related to perceptions of relevance

Young people suggested that that activity incentives (like bowling or Go-Karting) did work, however were not sustainable, and were beside the point of a group clinic. An alternative might be to make the group compulsory, or to peg it to the regular one to one clinic.

Finally, young people were keen that groups should not replace one to one clinic appointments. The importance of one to one time with a professional was clear throughout all the interviews, for discussing more personal issues. In addition, if the group clinic was part of the one to one appointment with the clinician, young people may be more likely to attend.

Staff sessions

Many of the same issues came up in the staff sessions, with similar conclusions. These included:

- **Role of the group clinic:**
 - **Need to tackle everyday life as well as medical issues:** “*I think with Type 1 teenagers, you can’t separate the disease with the life, because it’s so together, their life is taken over by Type 1 diabetes, they go for their first*

romantic meal at McDonald's, they've got to go and inject themselves, do I tell him I've got to inject myself? Things like that really does affect them. And I think you can't separate life from the disease." On the other hand, the balance is important so that some clinical support is included *"there's a lot of chatting that I sit in and listen to. I'm sometimes more apprehensive about the level of medical advice that seems to be shared among people than they are."* Staff also wondered whether young people could decide the themes for the focus of the next group, allowing the group some autonomy over content.

- **Practicalities**

- **Age.** Practitioners also debated – again without conclusion – the challenges of different kinds of age group banding within groups.
 - **Group size.** Practitioners reached a similar conclusion as the young people with respect to group size, concluding that a minimum would be two, but the optimum size would be five to seven, with eight a definite maximum. In addition to size, practitioners raised the issue of whether or not the group was going to be assumed to be a longer term commitment.
 - **Which young people?** The different dynamics of possible groups were discussed including younger people, young people with Type 2 diabetes who have a family context for their diabetes, years since diagnosis, etc. *"If you've got someone who's 25 and they've had diabetes for over ten years, they might not necessarily want or feel comfortable or feel the need to have a parent there and that might get in the way in their relationship."* Both benefits and challenges arose from combining young people with Type 1 and Type 2. As one staff member commented, *"we probably have the largest cohort of Type 2 between the age of 16 and 25 in the UK in Newham, so it's a substantive group."*
 - **Health or community setting?** In terms of where the groups were held, staff discussed the need to have an accessible location that was in a health setting, to reflect this was a clinic, not a simply a peer support group. Others discussed examples of clinics that have been successfully set in schools.
- **Who should be in the room in addition to young people?** Practitioners debated the importance for young adults of bringing siblings of a similar age, partners or friends to give them support, and, as with the young people, there was extensive discussion concerning parents. Practitioners felt that for teenagers it probably wasn't appropriate for parents to be in the room, but there would be ways of facilitating them to feel comfortable about that process at the beginning of the session, and maybe parents could be supported outside. In terms of other contributors, practitioners described models with quite wide ranges of professionals present including a diabetes consultant, nurses, psychologists, and dieticians. The participation of contributors would depend on prior agreement with young people.

- **Facilitator skills.** There was also discussion concerning the profession of the facilitator, and whether this should be a clinician, nurse or youth worker. Some staff felt more strongly that the group leader should be a healthcare professional who has facilitation skills and there shouldn't be too many healthcare professionals in the room, so that young people were not bombarded. Alternatively we discussed models where there is more than one leader, including a trained facilitator but also a healthcare professional.
- **Is the group a longterm arrangement?** Staff debated the differences between a clinic that could be 'dropped into' and a clinic that was designed to develop a more long lasting group. Different models may have different implications for rule setting.
- **Confidentiality and sharing** – Staff also reflected the need to be understanding about the possibilities of feeling uncomfortable and worried, or shamed, by comparisons within the groups. The importance of trust and a code of conduct were considered important. This also related to trust in the NHS – *“I think we need to tell them what it is that the NHS is getting out of it. My experience is they're usually quite suspicious, you know, what are you up to, why all of a sudden are you wanting to talk to me. One of the ways that we've found very helpful is to say, look, as an NHS we're doing it for these reasons, whatever they are, to what extent they're clinical, but we have to say to people, this is why we're making this change, this is what's in it for us. I think if you're honest with what's in it for you, then that's usually a way of building the trust. Nobody trusts someone who's just coming in altruistically.”*

There were also a number of issues that came up in the staff group but not with the young people. These included:

- **Measuring outcomes.** *“As a commissioner, I don't care how you get better outcomes for these young people as long as that's what you're reporting back to me and I can see that you're doing it in a cost-effective and it is patient-centred. So the fact that you are taking a co-production approach is already a good thing, but what we're looking to commission is outcomes, so what we're looking to have is young people with better disease management and therefore fewer complications and therefore less demand on other parts of the services.”* On the other hand, *“As someone who provides the clinic, I'm cautious about outcomes. We've just got to be a little bit careful about what kind of outcomes we're looking at. Because my big concern is, if you start engaging people who never turn up, it's a bit like [?], your markers of glycaemic index are actually going to get worse in the short term before they get better. And so I don't want then to be penalised for engaging people who never turned out for the last five years, because suddenly the HPA1C has gone worse.”*
- **Need for support of staff providing the groups.** As one staff member said, *“We've talked a lot about the users, and one of the things I think would be very useful is to see how we learn from and support the health professionals providing the group as we go along. Because just by doing the peer group, it's been very uncomfortable for people who this is a new model, something that hasn't been done before.”*

- **Dealing with unrealistic expectations raised by the group:** For example, “... because his best mate who comes to the group with him is on a pump, he just wants the pump. And so we’re having to deal with this expectation and manage it, very unsuccessfully, and we’re not very good at it, but we’ve kind of put them in that position, because they met through the group, they meet every weekend”.
- **Keeping clinical notes:** The staff talked about the fact that it was important to have clinical notes made about who had attended and what the focus of the session had been and some kind of feedback opportunity for the young people at the end.
- **Use of technology to supplement groups** This was raised as a possibility for further consideration, given the age group of the patients and their interest in social media, “It seems to me that a lot of the work that we’re doing around young people just becomes to the extent that they expect their technology to be absolutely part of this. And I think we need to be thinking about that virtual world that you create to support, because there may well be some extent that there are some things which actually the young people need everybody to be out of the room, parents, friends, health professionals, youth workers.”
- **How groups might evolve or grow organically,** possibly piggybacking on a pre-existing group such as young people who are transitioning to adult care at around the same time. Staff emphasised the need to be creative, and to consider how the clinics will be framed and operationalised. It may be that recruitment is undertaken over a distinct two month period, so that appointments are more likely to be roughly aligned, and setting a schedule of groups for a one year period. Staff commented that they could, for example, actually take that group of six people who come to the transitional clinic and say your first follow up appointment is a group clinic. “And those are the ideas I think a lot of us have “been coming up with, because you’re then kind of creating a group that’s semi-formed already.”
- **How to do something different within the NHS** “The NHS wants to shortcut, because it [a group] is quite resource intensive, it doesn’t produce measurable outcomes in the short term, and it doesn’t tick any of the boxes for the NHS. But in always going back to what the NHS is comfortable with, we never achieve any of the long term outcomes for the patients. So I think that’s just the challenge for the NHS, we like things to be neat”.
- **How to give enough resources** “we had a lot of nurses sitting in clinical settings with a 40% DNA, which seemed to us to be a really bad use of resources all round.” “...they are a very difficult group to get consistency in terms of attendance”.

4 Outcomes from joint session

The individual sessions and the joint discussion revealed that there were a number of shared themes, and young people and staff raised a range of similar issues and concerns, and suggested similar solutions. For example, the purpose of the group clinics was agreed as being beyond simply a medical education model. Mutual trust was important, not just among the young people but between them and the adults, and between everyone and the 'NHS'. An appreciation of the demands on young people and the need to fit in with their lives was clear.

The importance of the facilitator, the environment and the atmosphere were emphasised by everyone; *"I think what you said about facilitators was really important, and just the environment, the atmosphere that's created within the group, and the fact that it's non-judgemental but also that the facilitator doesn't dominate, or that other people aren't allowed to dominate. I think that's a really important thing."*

The sessions revealed a number of unresolved issues, where both staff and young people suggested various options, but where a 'right' answer was not obvious. There was joint agreement that quite a lot of effort was going to be required to work out how best to 'form' the groups, and how best to organise content and facilitate the sessions.

There was also shared concern about the sustainability of the groups, and how to encourage continued commitment to attend. Both patients and staff appreciated that it would take time for the groups to take shape, to clarify the aims, and feel comfortable with the other participants. As one staff member commented, *"...so I would put quite a lot of time into that forming process, and there will be time where people will move around, you might hop around three or four different groups before you get settled in a group. That's how it's been with any group I've been a part of, you rarely go along to the first one and find that the right one."* As another noted, *"...it's going to be an organic process, so we'll be looking at different ways that that might work, and we'll be very much led by the group, so that whether it works to have one group at one age and that might work in some places, or whether it works better to have groups of different ages or people who have had diabetes for different lengths of time."*

5 Conclusions and reflections

The co-design process demonstrated that both young people and staff shared similar ambitions for the new group clinic model in terms of bringing a more social and participatory approach to a medical issue. Both groups appreciated the particular life stage and life challenges for young people with diabetes in their teens and early 20s, and appreciated the positive role group clinics might be able to play.

How they will work in practice turned out to be something that will need to be tested; there were few hard-and-fast recommendations. However, it was acknowledged that there are challenges in fitting this new model into the existing NHS framework. This relates partly to the ability to be flexible and adaptive. It also relates to the need to dedicate enough resource to the clinics, and to ensure that they fit within NHS clinical frameworks as well as within young people's busy and sometimes chaotic lives. Much of this will need to be continually negotiated as the trial of the group clinics gets underway.

Conclusions from TOGETHER co-design

- A group clinic is a good idea for supporting diabetes self-management in young people and reducing feelings of isolation, particularly in local communities
- The purpose and benefits of group clinics (both for patients and for staff) need to be clear to everyone taking part from the outset. Everyone should be clear what they will get out of the process, and this should be an appealing outcome for them.
- A group clinic would not help young people discuss very personal issues, they would rather do that 1:1, and confidentiality in the group needs to be managed carefully. But groups could be a way of addressing wider health management challenges than just medical issues.
- Groups could potentially be combined with normal clinic visits and 1:1 time, or there may be other ways of 'pegging' groups to existing appointments or schedules.
- Young people's lives are hectic and they do not always prioritise their health. Attendance will be a real challenge. Clinic times need to fit around their regular commitments which are usually work or education.
- Young people are nervous of being judged for not taking good care of their health. Promoting feelings of safety, security, confidentiality and trust were important
- The facilitator role is critical and requires skills in youth participation

- The best combination of attendees' characteristics, content and other issues will probably need to emerge through trial and error. However, clinics should have a minimum of two people and a maximum of around 6 to 8.
- Parents are an important contingent, but should not be part of the regular groups.
- Group clinics may not fit easily into the existing NHS structure and constraints, and may need more (people) resources than anticipated to keep them going. It may also be necessary to be creative about how to measure successful outcomes and explain the benefits.

A limitation of the co-design work was the small number of young people who were able to participate. Engaging young people in the process turned out to be particularly difficult, despite considerable flexibility on the part of the participation team. This was partly because of constraints on recruiting young people (from the NHS Trust's perspective), but it also reflects on likely challenges in getting engagement with and commitment to the model once it is rolled out. This is not for lack of enthusiasm, but for other issues to do with busy lives. For this reason, and because more co-design was planned later, the celebration event was not included in this round of co-design but will be revisited as an idea later in the project.

In the second year, joint patient and staff groups will be reconvened to reflect on the learning from the initial 'roll out', and to consider revisions and improvements to the group clinic model. The ongoing co-design will also continue to inform interpretations of the findings from the parallel realist review (Papoutsis et al, 2017).

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Appendix 1: Co-production activity log

Activity	Patient group	Staff group	Joint patient staff event 1		Additional one to one interviews	Joint patient staff event 2
When	31.5.17	31.5.17	1.6.17		July/Aug	TBC
Facilitator	Jeremy	Emma	Jeremy and Emma		Jeremy	Jeremy / Emma / Ann
Consent	Desiree / Jeremy	Sarah / Shanti	Desiree / Jeremy	Sarah / Shanti	Desiree / Jeremy – either by telephone or from consent received at the workshops.	TBC
Content	Facilitated joint discussion using prompt questions and exercise circulated to team in advance	Facilitated joint discussion using prompt questions and exercises circulated to team in advance	Depending on attendance and outcome of workshop on previous day and attendance at this workshop we will either: <ul style="list-style-type: none"> a. Run the first 30 minutes as separate groups covering consent and looking at the outcome of the previous day's discussion and then join the groups together. b. Run 2 separate groups as on 31.5.17 		Additional interviews were planned to supplement work of joint group and allow more patient input. These supplemented the data from the groups using the same questions.	Potential to have part of the celebration event focused on a joint sessions with staff and patients to confirm outcome of co-production etc.
Other team members and role	Ann – support Chrysanthi – evaluation / notes	Sarah / Shanti observers plus notes	Ann – support Chrysanthi – evaluation / notes	Sarah / Shanti observers plus notes	Ann - support	TBC
Practicalities	Desiree bringing patient consent and Info forms.	Sarah bringing staff consent and Info forms.	Desiree bringing patient consent and Info forms.	Sarah bringing staff consent and Info forms.	Arranged by Jeremy & Desiree with input from Emma as necessary	TBC
Data collection	Recording if consent is in place plus flip chart and note taking				Note taking	Recording if consent is in place plus flip chart and note taking
Participants	Two young people	10-12 staff members	(1) Mother & daughter (patient); (2) 10-12 staff members Both groups together		Two young people	TBC