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TOGETHER study:

Co-designing group clinics for young adults with diabetes

Year 2 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

We used an experience based co-design process to develop a locally tailored model of group clinics, together with young adults, health professionals, clinical commissioning group members, primary care and voluntary sector representatives.

This second round of co-production was undertaken one year after the first round, after approximately nine months of group clinics had been underway. The focus of the second round was on suggestions for improving the model. The procedure mirrored the first round by including a session with young people (this time these were young people who had experienced a group) and a session with professionals who were involved in running groups.

Suggestions for improvements from the two co-production sessions included:

- Experimenting with minor changes to timing, but probably staying within the overall 5-8pm window
- Experimenting with the extent to which the groups are 'pegged' to existing hospital appointments and clinics
- Building into the model realistic expectations of attendance and engagement, but assuming that these will take considerable time to build up
- Continuing to encourage external speakers occasionally but ensuring they can fit in with the unique delivery model adopted by the group clinics.

1 The TOGETHER project co-design process

The TOGETHER project overview

Young people living with diabetes usually have their medical care delivered in 1-to-1 appointments with health professionals. However, living with diabetes while making the

transition to adulthood can be challenging, and young people sharing this experience in groups may be able to learn from and support each other.

The TOGETHER project is testing a 'group clinic' model for young people (16-25) with diabetes (Type 1 and Type 2) in two hospital trusts. A key part of the project has been working closely with young adults themselves to co-design the group clinics model, along with practitioners, youth workers and organisations such as Diabetes UK. Young adults are then invited to join the group clinics and their experiences are being studied closely to see if this care model might offer advantages. The protocol for the study was published in 2017 in *BMJ Open* (Papoutsi et al, 2017).

An outline of the process

We used an experience based co-design process to develop a locally tailored model of care, together with young adults, health professionals, clinical commissioning group members, primary care and voluntary sector representatives. Using a streamlined version of the Kings Fund Evidence based Co-design process, young people with diabetes and staff at the Barts Health NHS Trust were involved in initial discussions around possibilities and issues with the development of a new group clinics model. Key elements included separate and joint sessions with all stakeholders, with ongoing analysis of main themes. Patients and staff were encouraged to express emotions and experiences, rather than attitudes and opinions. These were shared through informal discussions and storytelling to identify opportunities for improvement and adaptations to service design. The focus was on the functionality (usability) for patients and staff. The co-design process was led by the Association for Young People's Health, an external voluntary sector partner.

The full 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 with experienced based co-design and more streamlined versions of the process are being developed that draw on pre-existing filmed material. The particular challenge of working with young people and needing the material to be directly relevant to them meant that this wasn't an option open to us at the time of the project. We relied instead on audio taping and verbal feedback at the joint meetings.

The first round of co-production was undertaken in 2017 and was written up in our Year 1 co-production report, which can be downloaded from the TOGETHER project website. Following a period of implementation in early 2018, a second round of co-production was undertaken in November/December 2018, in order to consider refinements to the model.

Results from the first round of co-production

In summary, the first round of co-production involved separate and joint discussions for patients (young people) and staff, facilitated by the Association for Young People's Health. Results suggested:

- 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.

- Overall, similar issues and concerns were raised by young people and staff, and both groups had similar ambitions for the new group clinic model: to bring a more social and participatory approach to a medical issue.

- For both young people 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 patients individual consultant/nurse 1:2:1 sessions.

- There was appreciation of the particular life stage and life challenges for young people with diabetes in their teens and early 20s, and of the positive role group clinics could potentially play. Both groups agreed that group clinics should play a role beyond simply a medical education model, to include clinical content.

- Both groups raised issues of trust, confidentiality and non-judgemental tone. 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.

Methods for second round of co-production

The second round of co-production was undertaken one year after the first round, after approximately nine months of clinics had been underway. The focus of the second round

was on suggestions for improving the model. The key questions that we were taking back to participants included:

- If we wanted to change the model, what would that look like? (eg, more peer led? How? Amending the group dynamics?)
- Issues with engagement, thoughts on changes to process, role of youth worker?
- Do we need more work before and after groups with young people in order to prepare/debrief?
- How is the relationship between the different professional groups working, and does this need tweaking?

The procedure mirrored the first round by including a session with young people (this time these were young people who had experienced a group) and a session with professionals who were involved in running groups.

The methods for the two groups in the second round included:

- <u>Introductions and context – 15 mins</u>
    - Thank participants for taking the time to contribute. Introduce facilitator and any other observers in the room, clarify their role and what they will be doing
    - Explain consent; reminder form previous signed, and consent for documentation (audio recording/notes/paper).
    - Explain what is this about - Looking at the feasibility of group clinics for young people, does not require participants to share personal, and possibly sensitive, facts about themselves. They are in fact experts through experience, and this is why they have been asked to participate. Sharing experience & emotions rather than attitudes and opinions.
        - *The project is exploring the potential for young people to see diabetes clinician/s in a group.*
        - *It is looking at the potential for harnessing peer group power to support better care for young people –e.g the opportunities for group discussion in a group setting etc.*
        - *This round of co-production is a chance to 'stock take' and reflect, in case we want to make changes.*

    - Explain the co-production process - Explain the context of co-design, how their opinions will be used, and what the project's goal are and what comes next.
        - *Kings Fund process*

- *Explain confidentiality – not attributing individual comments. Check consent for recording.*
- *Discussion not an interview*
- *No right or wrong answers*
- *You should feel free to raise other issues that we haven't thought about*

- Ask stimulant questions (see above), approximately 30-45 minutes for discussion

- Offer closing comments
  - Are there any further last minute points, or questions?
  - Explain what will happen next and how these ideas maybe carried forward. Also make sure to manage expectations for change and further development.
  - Big thank you

Due to availability of young people and staff, and the time and logistical pressures faced by both groups, they were derived from two different hospitals where group clinics were being piloted. The young people were at a hospital where group clinics were just beginning, and so had only experienced one group before the co-production session. However this had allowed them to see the model in practice before they commented. Those attending the staff session had been involved since the beginning of the pilot in a separate hospital and had planned / delivered a large number of group clinic sessions. We did not include a final joint session in this second round of co-production, largely for reasons of timing and practicalities.

2 Themes from second round of co-design sessions

(i) Young people session

- **Establishing rapport**: Young people reflected on importance of the ice-breaker activity at the start to warm up the session, and the importance of the establishment of ground rules. Thus, for example, "*I liked the confidentiality part, of like –it's us, staying here, no one knows after. It's good*". As one said*, "There are also some stories that only people with diabetes would understand".* There were also some thought provoking discussion about how much to share: "*If this is going to be our group, I'd be interested to know your backstories and when you got diagnosed, and just know a bit more about you so we feel kind of closer".*

- **Content:** Views both about focusing the session on one topic (eg diet), but also allowing time for other conversations and links between different topics. As one young person said *"I mean, just talk more about it, you know? And give stories, stuff like that*". It was also considered important to know what the topics were in advance, so that questions can be prepared. Young people also appreciated the involved approach*: "It wasn't just 'here's this card', it's like 'you guys do it and we'll all go through it, and everyone was involved*". Another topic suggested for discussion was '*motivation*'; or as one young person put it "*mental fortitude*". Finally the young people discussed the potential usefulness of brining in test results and discussing them together, "*Even if it's just like a problem day, we could bring it to the table and say 'has anyone else experienced this*?'". As one young person noted, it may be that some of the important information is word of mouth: "*It might be something that even these guys [staff] don't know that happens. Because they're not living with it every day. They just deal with it though us guys. But if we're doing something every day that isn't' a scientific, proven thing, it's happening, that might be the only way that people will figure out that it's a thing.*"

- **Value of the session:**
    - **Validation:** *"…sometimes you might think it's a stupid question and be afraid to ask, but if someone else goes 'I have a problem with that', you're like 'oh yes, it is a problem, let's deal with it'*.
    - **Meeting others** *"…to be honest, when I walked into this room and when you asked who's Type 1 diabetic, and you three put your hand up, I've only ever met Type 2s in my life. So my face might have been serious but inside I was like 'What? You guys actually exist?' You hear about it but I've never actually met another Type 1. It was just good to know you guys exist*".

- **Practicalities:**
    - **One steady group or flowing membership**. Views went both ways on this. *"…if we come back next week and three people don't turn up and it's three new people, you sort of have to just start again. And you don't get the group feeling that you guys are aiming for".* On the other hand there was appreciation that sometimes it may be useful to have, for example, gender specific sessions: *"Obviously there are some things that affect women that don't affect men. That affect your blood sugars, and these guys aren't going to be able to help with that. So it's pointless having a group session full of men to help with women's issues*". However there was consensus that around 6 people was a good number for a group.
    - **Timing**: Length of time: *"I think the timing is right, actually. The amount of time is good, not too long and not too short either because we need time to*

talk". On the other hand, "*if we do come with a lot of questions…we might then have another half an hour of questions…So that might be something that you guys have to plan"*. And also, time of the day was discussed. Generally young people felt 6pm would be best, but they did also acknowledge that this would not work for some young people who had work shifts in the afternoon and evening. The timing in relation to the clinic appointment was also mentioned, with one young person suggesting that "*I think it's nice being connected to the appointment. Because then you just have the afternoon of hospital and diabetes. But then if they were separate then after work would also be nice – because work can sometimes…I know they're not allowed to be arsey about you getting time off but they are....They don't want to pay you for not being there"*.

- **Amount and nature of contact pre- & post- session**: Young people had rather different perceptions of the amount of contact that had taken place in preparation for the meeting. Some were unsure what kind of contact they had received, or said they could not hear the message. Staff reassured young people that they had a mobile number and a single point of contact. There was a sense they would like contact in several forms to cover the bases – texts, and also a physical letter "*just in case*".
- **Internal or external presenters**. "*It would probably be nice to have experts in. Not that you guys aren't experts, but I mean people that we don't know*".

(ii) Staff session

Three project staff and an AYPH staff member were involved in the staff discussion session. As in the first round of co-production, the themes raised were similar to those raised by the young people.

- **Trust, relationship building**. This clearly takes a lot of time and this has to be built into the model. Staff noted that "*we know it takes a long time for us to start building relationships, to start trusting us*". This extends outside the clinic, so that trust is also making young people clear you are available for them at other times even if they have not attended the group: "*And then slowly, slowly, these are the same young adults I've seen a change in their attitude, where they've become more responsive*". Eventually, the staff concluded "*I think they are trying their best, they are actually making an effort to be there. And if they're not there, they're letting us know. Whereas before, at the beginning, if they weren't coming we didn't hear from them, they were ghosts*". In fact, this is a process that takes several years, and it builds up as *"…new young people that are coming to group clinics are seeing the relationship of the other peers that have been regularly attending*". The staff also

included (unlike the young people), issues of managing conflict and managing expectations. Appreciating the time all this took was essential to a successful working model: "*If you have their trust then they'll engage with you as much as you want them to engage, but they have to trust you*".

- **Importance of key staff**. Value of the youth worker *"…I think it's having [youth worker], no doubt about it. It's also, when they do attend clinics, you're building that relationship and you're keeping that momentum…being responsive to their needs*".

- **Content**: Generally the staff felt this was appropriate. One commented "*The amount that these young people are achieving is amazing, you know*

- **Practicalities**
    - **Icebreakers**. The staff agreed these were useful. Indeed, one commented that introducing the icebreakers had "*changed everything*" but, with their longer experience of the clinics, they felt that the time and place for them was in the earlier sessions, and that they were not as important as time went by.
    - **External speakers:** Staff agreed these were important, but the ability of the speaker to engage with the group was very important*: "…they need to have experience with young people. And be very welcoming to these young people and understanding of their situation, and that they've come in their own time, voluntarily, and that they're already under a lot of immense pressure."* External speakers also need to make the sessions as interactive as possible in the spirit of the group model.
    - **Timing**. The staff also raised this as an issue, and felt that 5-7pm perhaps was not ideal, particularly for those at work. They suggested pushing it back to 6pm, but appreciated 8pm was a late finish. Like the young people they could not offer an idea solution, but they did feel that there was a group of young people being missed by the current timing. Saturdays were not considered practical for a number of reasons including the fact that the current location would not be open. Timing also had to be open to varied arrivals, and the clinic needed to anticipate this. Thus, *"I don't think they are intentionally trying to come in late or they're running late or they're being lazy and turning up late, I think it's more because of the age group that they are, 16-25, college, university work"*. Staff noted *"I'd rather they come late than not come at all. We've got to make acceptance for them coming at that time".*
    - **Whether to incorporate into normal delivery.** There are several different issues here. One is the issue of substitution, where the clinic can take the

place of one-to-one, but the staff felt (as do young people, generally), that the clinic has to be complementary"…*this particular group clinic, the way I look at it, incorporates education, clinical support, peer support and it does not take away the one-to-one; there is definitely a need for one-to-one.* On the other hand, the staff felt that the clinics would be strengthened by being part of normal service delivery not an optional extra, a part of routine care. "*Because you have your one-to-ones but you also have group clinic in addition. So in addition rather than in isolation*". Each provide their own important contribution to care.

- **Group numbers:** Staff also confirmed 6-8 was the optimal number of attendees. However it was very important to be realistic, and that only achieving two out of 10 who have agreed to come should not be regarded as failure.
- **Communication between professionals**: Staff noted that this was essential to make the clinics work smoothly. This was partly about defining roles and responsibilities, but also about how to communicate. There is a certain amount of double checking that has to happen, and communication over who had heard from which young people. There is also a considerable amount of texting and phoning back and forth over arrangements and updates. Altogether "*It's quite labour intensive*". However a benefit appears to be that engagement by the young people increases as a result, "*it's just keeping up with that, making them feel supported, that we are there".*

Conclusions: Improving the model

Overall the second stage of co-production confirmed the messages we heard in stage one but provided some more detail about how the model could be optimised. The role of the youth worker and other staff who are able to engage with young people effectively was particularly important and this included a focus on building group relationships, establishing boundaries and confidentiality. Young people liked the youth focused nature of the groups and the space that they gave them to raise issues about their diabetes that they wouldn't elsewhere.

Again, as with the first round of co-production, there was a lot of synergy between the messages from the two groups. Overall key suggestions for changes to the group model included:

- Experimenting with minor changes to timing, but probably staying within the overall 5-8pm window

- Experimenting with the extent to which the groups were 'pegged' to existing appointments and clinics
- Building into the model realistic expectations of attendance and engagement, but assuming that these will take considerable time to build up
- Continuing to encourage external speakers occasionally but ensuring they can fit in with the unique delivery model adopted by the group clinics.

As one staff member said, *"It has been quite a journey. A slow, slow journey, but on the positive side it's actually grown…it's been a work-in-progress but…the engagement in the last few clinics has been better than it was.*" This suggests that there is nothing fundamentally 'wrong' with the clinic model as it is unfolding, but that the unfolding is very much part of the process.

Acknowledgements

With very many thanks, as always to the participants in the co-production groups for their time, energy and invaluable contributions. We're also grateful to the other staff who helped with the practical arrangements and welcomed us into their hospitals.

Outputs to date

Papoutsi C, Hargreaves D, Colligan G, et al. (2017) Group clinics for young adults with diabetes in an ethnically diverse, socioeconomically deprived setting (TOGETHER study): protocol for a realist review, co-design and mixed methods, participatory evaluation of a new care model. *BMJ Open* https://bmjopen.bmj.com/content/bmjopen/7/6/e017363.full.pdf

Hagell A and Sachs J (2018) *TOGETHER study: Co-designing group clinics for young adults with diabetes*. London: Association for Young People's Health http://www.youngpeopleshealth.org.uk/wp-content/uploads/2018/01/AYPH-co-production-report-Nov-2017.pdf

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