

RESEARCH: CARE DELIVERY

Young adults with type 1 diabetes and their experiences with diabetes follow-up and participation in the DiaPROM pilot trial: A qualitative study

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Abstract

Aim: To explore young adults' experiences of outpatient follow-up appointments, completing electronic Patient-Reported Outcome Measures (PROMs), and using the Problem Areas In Diabetes (PAID) scale during the Diabetes Patient-Reported Outcome Measures (DiaPROM) pilot trial.

Methods: We performed a qualitative study among 19 young adults (aged 22–39 years) with type 1 diabetes who participated in the pilot trial. Between February and June 2019, we conducted individual, semi-structured telephone interviews with participants from the intervention and control arms. We analysed the data using thematic analysis.

Results: Our analyses generated three themes, each with two subthemes: (1) Follow-up with limitations; (i) Marginal dialogue about everyday challenges, (ii) Value of supportive relationships and continuity, indicate that previous follow-up had been experienced as challenging and insufficient. (2) New insights and raised awareness; (i) More life-oriented insights, (ii) Moving out of the comfort zone, suggest mostly positive experiences with completing questionnaires and discussing the PAID scores. (3) Addressing problem areas with an open mind; (i) Need for elaboration, (ii) Preparedness for dialogue, indicate that both openness and explanations were vital in the follow-up.

Conclusions: Participants characterised the previous follow-up as challenging and insufficient. They described completing and using the PAID as somewhat uncomfortable yet worthwhile. Our findings also suggest that by utilising diabetes distress data alongside health and biomedical outcomes, consultations became more attuned to the young adults' wishes and needs, mainly because the dialogue was more focused and direct. Hence, the PAID has the potential to facilitate person-centredness and improve patient–provider relationships.

KEY WORDS

diabetes mellitus, empowerment, outpatient care, patient-centred care, professional–patient relations, self report, type 1 adult

1 | INTRODUCTION

Managing type 1 diabetes is a persistent activity performed outside the diabetes care setting. Due to the nature of the disease, self management extends beyond glycaemic control and other biomedical outcomes, also affecting emotional health and social functioning.¹ Finding a balance between diabetes and living can be challenging regardless of age but especially so in young adulthood.² Experiences of burden, stress, anxiety and/or concern that arise from daily self management are referred to as diabetes distress.³ About one-third of adults with type 1 diabetes will experience distress levels likely to impact on self management and clinical outcomes.⁴ Furthermore, diabetes distress is more prevalent in younger adults than other age groups² and associated with problematic self management behaviours and poor glycaemic control.^{5,6} However, achieving recommended glucose targets does not necessarily exclude distress.³ Diabetes distress is viewed as a predictable response to having diabetes, not as psychopathology, and should, therefore, be addressed in routine diabetes care.³

For more than two decades, diabetes guidelines and position statements have acknowledged person-centred approaches to promote optimal well-being and disease management.⁷ Recommendations include routine assessment of psychological, emotional and psychosocial factors, such as diabetes distress, to identify problems and improve health outcomes. Diabetes distress can be assessed using Patient-Reported Outcome Measures (PROMs).³ Previous research suggests that PROMs can improve chronic care delivery by assessing, identifying and monitoring health outcomes, improving patient–provider communication, and promoting involvement in self management.⁸ However, recent studies indicate that healthcare providers (HCPs) still place excessive focus on biomedical outcomes compared to those that people with diabetes find important.^{9,10}

Guided by the Medical Research Council's framework for developing and evaluating complex interventions,¹¹ we have designed, feasibility tested and piloted an intervention to address diabetes distress in the Diabetes Patient-Reported Outcome Measures (DiaPROM) trial.^{12–14} The pilot trial targets young adults (age ≥ 18 to <40) with type 1 diabetes receiving outpatient follow-up and is described in detail elsewhere.¹² Briefly, we used the 20-item Problem Areas in Diabetes (PAID) scale to identify distress sources and intensity.^{15,16} Items are scored from 0 'not a problem' to 4 'serious

Whats' New?

- Diabetes distress is common among young adults with type 1 diabetes.
- We found that the Problem Areas in Diabetes (PAID) scale encouraged reflective thinking, promoted the young adults' narratives and facilitated person-centred dialogue in consultations.
- Implications are that healthcare services need to adapt to and acknowledge young adults' wishes by addressing diabetes distress during appointments. However, continuity of care and development of young adult–provider relationships are essential ingredients for utilising the PAID in the follow-up.

problem' and transformed to a 0–100 scale, where scores ≥ 40 are considered seriously elevated. Before the annual appointment with a physician, all participants ($N = 79$) completed the PAID on an in-clinic touchscreen computer and were randomly assigned (1:1) to an intervention ($n = 39$) or control arm ($n = 40$). In the intervention arm, physicians reviewed and discussed the PAID with the participants, guided by a manual about how to interpret and act on the scores. Twenty-three individuals reported a score ≥ 30 or at least one item scored ≥ 3 , therefore qualifying for additional diabetes specialist nurse consultations, of which 17 accepted. To lessen or prevent serious distress, the nurses reviewed and discussed reported problem areas with the participants, guided by a study manual with specific person-centred communication techniques (active listening, asking open questions, responding, summing up and agreeing on goals and actions to take). Control arm participants received standard outpatient care with no review of scores. Finally, all participants completed the PAID again at 12 months (reported elsewhere).

We have conducted two qualitative studies alongside the DiaPROM pilot trial to inform the quantitative findings by exploring participants' and HCPs' experiences and views on feasibility and acceptability.¹² The findings from HCP experiences are published.¹⁷ In the present study, we aimed to explore young adults' experiences of outpatient follow-up appointments, completing electronic PROMs, and using the PAID scale during the DiaPROM pilot trial.

2 | PARTICIPANTS AND METHODS

2.1 | Study design

We performed an exploratory qualitative study among DiaPROM pilot trial participants. Our approach was inductive and descriptive, focusing on experiences with outpatient appointments and specific pilot trial components.

2.2 | Setting and participants

We undertook the randomised controlled pilot trial and qualitative studies at a Norwegian diabetes outpatient clinic.¹³ The clinic employs endocrinologists, physicians specialising in endocrinology (or other internal medicine specialities), diabetes nurse specialists and health service secretaries. About 1500 adults with type 1 diabetes were registered there in 2019. Our eligibility criteria for the present study were pilot trial participation with completed 12-month follow-up. We sent study invitations to the 67 eligible participants 3–7 days after their 12-month follow-up and asked them to respond by e-mail, telephone or SMS. None replied within 14 days; therefore, we sent SMS reminders. Finally, 19 individuals responded positively: age 22–39 years, diabetes duration 5–32 years (Table 1); eight control arm and 11 intervention arm participants, of which six had received additional nurse follow-up.

TABLE 1 Characteristics of adults with type 1 diabetes participating in the DiaPROM pilot trial interview study

	Total	Intervention arm	Control arm
Participants	19 (100)	11 (58)	8 (42)
Women	11 (58)	6 (55)	5 (63)
Referred to nurse follow-up	6 (32)	6 (55)	NA
Age (years)	30 ± 5.2	29 ± 4.3	31 ± 6.3
Diabetes duration (years)	16 ± 7.4	17 ± 8.0	16 ± 7.1
Late complications*	4 (21)	2 (18)	2 (25)
Insulin pump therapy	12 (63)	7 (64)	5 (63)
Continuous glucose monitor	10 (53)	6 (55)	4 (50)
HbA1c (mmol/mol)	59 ± 11.7	58 ± 9.1	59 ± 15.3
HbA1c (%)	7.5 ± 1.1	7.5 ± 0.8	7.5 ± 1.4

Data are n (%) or mean ± SD. NA = not applicable.

*All cases of untreated retinopathy.

2.3 | Data collection

We offered individual interviews face-to-face or by telephone. All participants chose telephone interview. Between 26 February and 24 June 2019, the first author conducted and audio-recorded the interviews (average duration 39 minutes). The semi-structured interview guide received minor adjustments after the first two interviews (Data S1). First, participants in both trial arms were invited to share experiences with previous follow-up. Next, all participants were asked about electronic completion and relevance of the PROMs. Also, we encouraged intervention arm participants to share experiences with the physicians' review of the PAID scores and, where relevant, with attending additional nurse follow-up. The first author transcribed the interviews verbatim and checked the transcripts against the recordings for accuracy. We obtained clinical and socio-demographic characteristics from the pilot trial dataset. At the time, these characteristics were unknown to the interviewer.

2.4 | Data analysis

We analysed the data using thematic analysis, which focus on identifying, analysing and reporting patterned meaning (themes) across a dataset.¹⁸ Thematic analysis is theoretically flexible and characterised by an iterative, rigorous process of data familiarisation, open-coding, development of themes and revision. We applied an inductive approach and combined semantic and latent levels of analyses. The Norwegian-speaking authors (IH, MG, RBS, SSL, AKS, BCHK, AH) which constituted the analysis team, first read and reread all interviews to familiarise with the dataset. Next, each author recorded their preliminary ideas and generated initial codes. The team then met for two workshops. In the first workshop, each member shared initial thoughts and preliminary codes. We discussed features relevant to the aim, collated codes by pattern, prepared a schematic overview and formed candidate themes by identifying similarity and clustering. In the second workshop, we reviewed, discussed and revised the candidate themes, which also included creating new codes and themes for data falling outside the previous coding. IH continued the process and drafted the paper. Finally, we identified meaningful, coherent patterns and agreed on themes and subthemes.

2.5 | Ethics

The study received ethical approval by the Western Norway Regional Committee for Medical and Health Research Ethics (2017/1506/REK vest). This study was specifically described in the pilot trial's written information. All participants provided written consent and could withdraw at any

time, without giving a reason and without it affecting their follow-up. Participants chose the interview method and decided on timing. Audio-recordings were started after the interviewee had consented and pauses were provided if needed. Afterwards, participants were given time to debrief and, if deemed necessary by the interviewer, provided with information on clinical supervision and support. Participants' identifying information was removed from the transcripts before a digitally encrypted document was shared with the analysis team. Data are stored on Haukeland University Hospital's secure research server.

3 | RESULTS

The analyses generated three themes: 'Follow-up with limitations', 'New insights and raised awareness' and 'Addressing problem areas with an open mind', each with two subthemes (Table 2).

3.1 | Follow-up with limitations

The participants described previous outpatient follow-up as challenging and insufficient, which is further explored in the subthemes 'Marginal dialogue about everyday challenges' and 'Value of supportive relationships and continuity'.

3.1.1 | Marginal dialogue about everyday challenges

Several participants characterised the follow-up as challenging and conveyed hesitance and reluctance about attending, especially physician check-ups. One expressed:

“[It is] a bit like sitting for an exam, going to a check-up. I don't think it's deliberate, but you feel a bit like they're wagging a finger, right.

TABLE 2 Themes and subthemes generated by the analyses of interviews with 19 young adults with type 1 diabetes their experiences with outpatient follow-up and participation in the DiaPROM pilot trial

Themes	Subthemes
Follow-up with limitations	Marginal dialogue about everyday challenges
	Value of supportive relationships and continuity
New insights and raised awareness	More life-oriented insights
	Moving out of the comfort zone
Addressing problems areas with an open mind	Need for elaboration
	Preparedness for dialogue

You worry about your HbA1c because then you might be seen as 'a not so good diabetic'. That kind of follow-up is the reason why I've hardly attended. It's been a problem.”

(Participant 8, control arm)

According to interviewees, annual check-ups typically focused on biomedical 'numbers', for example, blood tests, glucose values and insulin doses, often at the expense of conversations about everyday life. However, opinions varied. Some experienced that such check-ups were not worthwhile. One participant put it like this:

“I feel that I'm only there for them [physicians] to tick off something on a checklist and do their job in a way. ... I feel that there's no point in being there then because what do I gain from them weighing me and measuring me? Uh. I don't feel that we're talking about important issues.”

(Participant 19, control arm)

Others stated that check-ups provided a sense of security about their disease management. While some did not know what to expect beyond information about test results. In addition, experiences were compared to previous paediatric follow-up, as described by one:

"I do expect to be able to talk to someone about diabetes itself and not just how the test results are, you know, bodily in a way. At the paediatric clinic, they were much better at that because there was more of a holistic focus there I felt. When I was transferred to the adult clinic, I felt they were less focused on that.”

(Participant 15, intervention arm)

The young adults conveyed being accustomed to questions like 'How are you doing?'. However, such inquiries were often perceived as superficial and difficult to address and therefore often answered half-heartedly, without promoting dialogue where they opened up. Although stating a wish to be asked about the emotional aspects of self management, they also expressed ambivalence due to previous unpleasant experiences. One said:

“I think it's a good idea to ask patients questions about what we think about our lives, our diabetes and situation. We're after all the ones who know best, but at the same time, I quickly feel that I'm put on the spot and that I have to answer very properly, and then I, like, don't really get to

answer what I think. I feel that it's a pressured situation. Uhm yeah."

(Participant 16, intervention arm)

Moreover, participants specified that the pilot trial's focus on diabetes distress further highlighted that previous follow-up had been deficient. One stated:

"That [questionnaire] underlined the fact that there are very many issues a physician can bring up. So, I mean, a lot is missing there. At least when you're there just once a year and if you're a 'good patient'."

(Participant 15, intervention arm)

3.1.2 | Value of supportive relationships and continuity

The young adults expressed a wish to be met as a *person with diabetes*, not a *diabetes patient*, by empathetic and caring HCPs with diabetes expertise and communication competencies. However, many described negative experiences with the existing services, such as considering whether they were comfortable opening up to HCPs. This consequently affected conversations. One said:

"Everyone is probably professionally skilled, but not everyone, maybe, uh, I call it human understanding, communicates equally well. It's a bit to do with confidence, and it's to do with chemistry, but you don't want to automatically open up to everyone. While with physicians you know listen to what you say, it's okay to maybe open up a bit more."

(Participant 6, intervention arm)

In seeking trust-based and supportive relationships, they described wanting to become comfortable with sharing concerns and challenges, but with as few HCPs as possible. However, many had experienced rarely meeting the same physician twice. One participant described the importance of relational competence and continuity like this:

"A good relation is quite important for you to speak about things you might dread or be ashamed of. Or sorts of things that are about struggling with self-management or other things. So, I think about that relational competence bit and actually appreciating that there's some continuity. I think they still have some way to go in that regard."

(Participant 18, control arm)

The participants also reflected on the need for HCPs to be attentive to individual wishes and needs for them to experience being seen and heard. Compared to challenges usually conveyed to physicians, they expressed that they more often addressed emotional and psychosocial concerns with nurses. These challenges were considered less specific and more complex than biomedical outcomes. One described a diabetes nurse's contribution:

"The focus [in nurse appointments] is what's difficult. That's kind of the question when I come in. Like what's challenging and then we take it from there. So, I get to be a lot more involved, and I feel that I'm seen and heard, and if I'm having a bad day, she doesn't give up, and I think that's very nice."

(Participant 19, control arm)

3.2 | New insights and raised awareness

The young adults conveyed experiencing new-found insights and awareness concerning the complexity of diabetes after completing PROMs, which is described in two subthemes: 'More life-oriented insights' and 'Moving out of the comfort zone'.

3.2.1 | More life-oriented insights

Completing questionnaires made the young adults reflect upon their everyday lives, which enabled further insight about their situation, also regarding issues that some had not previously thought about. The realisation or increased consciousness about emotional and psychosocial aspects of diabetes self-management helped participants from both trial arms to reflect upon how they were feeling before engaging with HCPs. It also helped them understand that they were not alone in being faced with diabetes-related challenges, as described by one participant:

"I think the questions are very good, and I think they might help you think of other things to discuss with the physician. The way the questions are set up, and that maybe you feel that you're not the only one who can think about different things. That you're not alone with those thoughts and what you feel about your diabetes."

(Participant 17, control arm)

Furthermore, the PAID items were characterised as highly relevant, concrete diabetes-related concerns and challenges put into words. As some were made aware of possible yet unfamiliar

diabetes-related challenges, they expressed that inquiry into diabetes distress should have been part of the existing follow-up. One said:

"I mean, this is something I'll live with for the rest of my life, so it [diabetes distress] should've been opened quite early, so that one might've been prepared for things that can become difficult and that it can affect your head in many ways, plus your body too, physically. How your psyche and your head are affected by diabetes when you work with it all the time."

(Participant 3, intervention arm)

3.2.2 | Moving out of the comfort zone

Although the questionnaires mostly contributed positively, interviewees from both trial arms also shared a variety of challenges. In general, they found it difficult to decide on response options and characterised this as rating or placing themselves on a scale. The reflectiveness and increased awareness also evoked rather demanding thoughts about life with diabetes. Completing the items and the prospect of disclosing responses were labelled as moving outside one's comfort zone. They used words like *vulnerable*, *uncomfortable*, *exposed*, *scary*, *super close*, *genuine* and *real*. One participant articulated it like this:

"It's quite scary because you feel so exposed in one respect, and no one's seen that before... It's crazy how things get so real, both to yourself and to others when you sit and tick off 'how you feel' or 'how you are', or what you've been thinking and stuff."

(Participant 19, control arm)

The young adults also revealed insights about sincerity while completing PROMs, which varied between finding it unproblematic to choosing to size up the situation. They communicated that responses could be affected by insecurity about which HCP they were seeing afterwards. In addition, they conveyed that openness was interconnected with willingness for self-sincerity and evaluating this against sharing one's true problems. One said:

"Some questions [items] can be somewhat difficult and painful to respond to. If you really answer exactly the right thing, I guess that's really what can be a bit inhibiting, how honest you are with yourself. As a diabetic, you become a bit like... you lie to yourself sometimes (laughs), you think things are somewhat better than they

really are. I mean, it's difficult at times, but I think some awareness and thoughts about how you're actually doing is a good thing. I think that's healthy."

(Participant 11, intervention arm)

Overall, participants expressed appreciation about the emphasis on diabetes distress, which covered areas many were unfamiliar with discussing and could struggle with addressing at appointments.

3.3 | Addressing problem areas with an open mind

When using the PAID in consultations, the participants highlighted the importance of addressing problem areas with an open mind. This is further exemplified in the subthemes 'Need for elaboration' and 'Preparedness for dialogue'.

3.3.1 | Need for elaboration

Young adults in both trial arms communicated a need to elaborate on and share underlying experiences associated with their PAID responses. This was also deemed necessary by intervention arm participants since some experienced that HCPs placed greater importance into their responses than was intended. Hence, nuances, clarity and/or explanations were particularly important. One said:

"I felt that I responded honestly, but it was almost a bit ... the nuance that 'yes, I'm very worried and I think this is very scary and...', but it's not as if I can't manage, like, or it's not as if... Yeah, there was a nuance that disappeared somewhat because in a way it's possible to be quite worried but still not so bothered by it."

(Participant 9, intervention arm)

In addition, some discovered that the physicians were surprised by their diabetes distress scores but experienced increased understanding since the distress was acknowledged. They characterised this as sharing new insights into the challenges of seemingly 'well-functioning patients' and viewed it as an opportunity for physicians to engage with their distress and initiate dialogue.

3.3.2 | Preparedness for dialogue

Interviewees characterised the PAID as a tool used to focus on diabetes-related issues ahead of check-ups. Intervention

arm participants further stated that it served as a vent to communicate frustration and, without them having to initiate, as a conversation starter that facilitated a more constructive dialogue. One said:

"I think it was all right that the physician could see my [PAID] responses. Then the physician could address problem areas, or what I was dissatisfied with or worried about. We had something constructive to work from, it [the dialogue] didn't get as vague as... Yes, I find it difficult to put into words what I really want from appointments. It probably became more apparent in the questionnaire."

(Participant 16, intervention arm)

Completing the questionnaire made it difficult to postpone challenging issues. However, getting on track was considered positive, and using the PAID also contributed to an experience of being taken seriously. Nevertheless, intervention arm participants referred to additional nurse follow-up, conveyed not preparing for these appointments. Some also described a lack of flexibility where the PAID took up too much space and characterised the dialogue as unnatural and difficult for both parties. Furthermore, they conveyed that the nurses did not seem sufficiently prepared to receive, attend to or discuss their problems. Therefore, the follow-up did little to alleviate their distress. One depicted a consultation like this:

"It was a bit like: 'Yes, do you want to say anything about what you find difficult? No? Then we'll move on to the next item.' So, it was a bit like you felt that you exposed yourself a bit more than she was comfortable with."

(Participant 6, intervention arm)

However, some participants defended the nurses and argued that they simply followed the study manual, further specifying that the PAID had set the agenda. Nevertheless, the overall essence communicated by the young adults, was that using the PAID was somewhat uncomfortable but still worthwhile.

4 | DISCUSSION

In this study, young adults described finding previous follow-up lacking in content and continuity of care, hindering the development of supportive patient-provider relationships. Furthermore, our data provided insights about how they experienced and were affected by completing the PAID and the importance of an open-minded approach while addressing diabetes distress in consultations. We have identified, therefore, important considerations for further trial development.

In keeping with other studies, we identified that young adults want the complexity of diabetes to be addressed at appointments.¹⁹⁻²¹ Their calls for continuity in care and person-centred, holistic approaches to follow-up extending beyond biomedicine and highlighting motivational and emotional challenges, are also supported in the literature.^{9,10,19,22} Biomedical outcomes are undeniably important but do not necessarily reflect aspects most important to people with diabetes.^{9,23} In this pilot trial context, participants conveyed appreciation about the PAID's content in addition to how it functioned as an eyeopener and promoted dialogue about important matters. In accordance with PROM literature, it created an opportunity for reflective thinking and validated their narrative,^{8,24,25} which in turn seemed to facilitate and enhance the patient-provider dialogue.⁸

Our findings also support the 'red flag' approach (targeting higher scored items), which can help identify specific distress sources and thereby narrow the focus in consultations.^{3,16} However, sharing PROM data can be difficult due to individual factors and/or patient-provider interpersonal factors. This suggests that when collecting PROMs in clinical settings, we need to be aware of selective reporting and other biases possibly affecting self-report and subsequently score interpretation.²⁶ Furthermore, our data emphasised the initiation of dialogue about underlying rationales behind responses to specific items, providing further insights about the young adults' lived experience. In a related study, HCPs described striving to balance recommendations for biomedical measurements with addressing young adults' emotional concerns due to limited resources and organisational challenges.¹⁷ However, this clinical conflict was not linked to unwillingness in applying supportive, person-centred strategies.

For people with diabetes, relationships with providers are essential for their ability to self-manage and have been shown to influence behavioural, emotional and biomedical outcomes.²⁷ Likewise, good quality relationships seem imperative for the beneficial use of PROMs in the clinical context. Adding the PAID may serve as a catalyst for starting dialogues about diabetes distress and may provide important insights that complement biomedical measures. However, for this approach to contribute, the essential ingredients are how the PAID information is used and how clinicians communicate.²⁴ Overall, the HCPs require further training in using dialogue tools. Since the development of the pilot trial, new evidence-based resources are available that will be useful for this purpose.^{3,28}

4.1 | Strengths and limitations

We have previously reported quantitative data regarding the feasibility and acceptability of the proposed DiaPROM trial.^{13,14} In this study, all interviews were performed after

the 12-month follow-up to avoid influencing quantitative data and outcomes.²⁹ We consider the qualitative approach a strength for the research project as it allowed for further exploration of the participants' experiences. We have gained insights about contextual factors such as the follow-up the participants were accustomed to before the pilot trial, in addition to intervention acceptance, fidelity and delivery that will aid further trial development.¹¹ Credibility and confirmability were strengthened by the research team's extensive diabetes knowledge and by involving researchers with considerable qualitative research experience in the analysis.³⁰ Furthermore, we used reporting standards to improve study transparency and credibility.²⁹ However, interviews concerning the previous follow-up should ideally have been performed prior to the pilot trial. Also, we had limited information about the HCPs previous training and general attitudes towards consultations, which may have affected the participants' experiences. Although our findings may not be directly transferable to other contexts, we believe that HCPs and people with diabetes will recognise at least parts.

5 | CONCLUSION

Our data provide insights into how young adults with type 1 diabetes experienced the DiaPROM pilot trial's contextual circumstances. Participants characterised the previous follow-up as challenging and insufficient. They further described completing and using the PAID as a somewhat uncomfortable yet worthwhile experience. Our findings also suggest that by utilising electronic self-reported diabetes distress data alongside health and biomedical outcomes, consultations became more attuned to the young adults' wishes and needs, mainly because the dialogue was more focused and direct. Therefore, the PAID has the potential to facilitate person-centredness and improve patient-provider relationships.

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CONFLICT OF INTEREST

None declared. Views expressed are those of the authors and not necessarily those of the Norwegian Nurses Association, the Western Norway University of Applied Sciences, the Norwegian Diabetes Association, or the National Institute for Health Research (UK).

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SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section.

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