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The development and delivery of a female chronic pelvic pain management programme: a specialised interdisciplinary approach

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Hannah Twiddy¹, Natalie Lane¹, Rajiv Chawla¹, Selina Johnson¹, Alison Bradshaw¹, Shaireen Aleem² and Lucinda Mawdsley¹

Abstract

Context/Background: Chronic pelvic pain (CPP) is a physically and psychologically debilitating condition. European Association of Urology (EAU) Guidelines (2013) and Royal College of Obstetricians and Gynaecologists (RCOG) guidelines (2012) place strong emphasis upon multi-speciality assessment and liaison, as well as interdisciplinary assessment and intervention in reference to the management of CPP.

Objectives: The aim was to introduce and describe the development and delivery of an interdisciplinary pain management programme (PMP), at a Specialised Pain Management Centre in Liverpool, United Kingdom, for women diagnosed with CPP.

Method: The format and content of the CPP PMP at The Walton Centre, Liverpool, is described and the preliminary results from the CPP PMP are presented.

Results: Preliminary data suggest that outcomes on the specialised CPP PMP indicate that patients are able to make clinically important change across a range of outcome measures. Moreover, these results compare favourably to the established PMP for generalised chronic pain when comparing clinically significant outcomes with the Walton Centre's (a tertiary-level pain management centre) 2013 PMP Audit document. Patients attending the CPP PMP positively appraised the PMP and felt it was useful and supportive to be in a group dedicated to CPP.

Conclusions: This article presents some preliminary results that suggest there is value in delivering a specialised multidisciplinary PMP for this group. There is a clear need for further clinical research into the effectiveness of similar interventions for CPP, including the early identification of those CPP patients who may benefit from both multi-specialty and interdisciplinary management.

Keywords

Chronic pelvic pain, chronic pain, pain management programme, cognitive behavioural therapy, selfmanagement, multidisciplinary team, interdisciplinary team, rehabilitation programme, psychology, occupational therapy, physiotherapy, uro-gynaecology, pain medicine

Introduction

Chronic pelvic pain (CPP) is a debilitating condition which has been reported to affect approximately 1 million women in the United Kingdom.¹ CPP is defined as persistent pain of minimum 6 month duration in the lower abdomen or pelvis.² The negative psychological, behavioural, cognitive and sexual consequences of CPP have been acknowledged in the European Association ¹Pain Management Programme, The Walton Centre NHS Foundation Trust, Liverpool, UK ²Gynacology and Obstetrics, Southport and Ormskirk Hospital NHS Trust, Southport, UK

Corresponding author:

Hannah Twiddy, Pain Management Programme, The Walton Centre NHS Foundation Trust, Jubilee House, Longmoor Lane, Fazakerley, Liverpool L9 7LJ, UK. Email: Hannah.twiddy@thewaltoncentre.nhs.uk of Urology (EAU) Guidelines 2013 definition of CPP and Royal College of Obstetricians and Gynaecologists (RCOG) guidelines (2012).^{3,4} The guidelines place strong emphasis on the biopsychosocial consequences of CPP and the need for interdisciplinary and multidisciplinary care. This is also echoed by the British Pain Society (BPS) patient pathway map for CPP.¹

Psychosocial factors have long been considered significant in understanding an integrated and full picture of complex chronic pain conditions.⁵ Emotional distress associated with pain and disability can have debilitating and marked effects on an individual's quality of life (QoL).⁶ Hence, it is of little surprise that women with CPP often report depression, anxiety and reduced sexual function.⁷ These latter difficulties are commonly linked with desires to start a family, pregnancy and childbirth.

There is long-established evidence for the effectiveness of cognitive behaviour therapy (CBT) in the management of chronic pain in the form of a multidisciplinary pain management programme (PMP).^{6,8,9} It has been suggested that psychologically based treatments can be effective in the management of CPP in addition to medical and surgical management.^{10,11} Moreover, there has been recent publication in support of multidisciplinary CPP services, including a male CPP PMP: the LINK PMP.¹² In the context of the evidence of heightened levels of psychological distress and painrelated disabilities, a clear rationale can be seen for the provision of a PMP designed to support and promote self-management strategies within this pain population.

Context for the development of specialised PMPs for CPP

The Clinical Reference Group (CRG) for Specialised Pain Services (National Health Service (NHS) England)¹³ notes many chronic pain patients can be managed well in the community or within secondarycare services. It has been recognised that the management of CPP is challenging and individuals with CPP often do not present as a homogenous population. However, more complex presentations may require highly specialised assessment and treatment that incorporates both multi-speciality assessment and interdisciplinary management. The Pelvic Pain Pathway devised by the BPS1 states that when pain management remains problematic following standard management, then a multi-speciality assessment and an interdisciplinary approach is required. This approach should include an integration of medical, psychological and sexual elements.

In the context of these recommendations and guidelines for the clinical management of complex chronic pain patients, a team of clinicians within the Walton Centre pain service devised and piloted the delivery of a CBT-based PMP for women with a diagnosis of CPP; the PMP team based at The Walton Centre is a tertiarylevel service that aims to deliver specialised chronic pain management assessment and interventions.

This article will focus upon intervention for those CPP patients treated within this specialised PMP.

Aims of this article

- The aims of this article are as follows:
- To describe the context and rationale for the development of a PMP for women with complex CPP;
- To outline the process and value of multi-speciality and interdisciplinary assessment of CPP patients;
- To present the specific content of a CBT-based PMP for female CPP patients from a multidisciplinary perspective;
- To present the preliminary results and outcomes from the first CPP PMP at The Walton Centre.

Method

Multi-speciality and interdisciplinary assessment

The Walton Centre is a tertiary-level pain management centre commissioned by NHS England to provide specialised services for patients with chronic pain. This specialist chronic pain management assessment team sees approximately 600 patients annually in clinic. In the initial stages of developing a specialised CPP service, key multi-speciality links were made. A clinic was developed to provide initial assessment and treatment recommendations, comprising a Consultant in Pain Medicine with a special interest in pelvic pain, a pain management Specialist Clinical Psychologist with previous experience working in both sexual health and psychosexual therapy and a Consultant Uro-Gynaecologist. This resulted in an additional (specialist) referral stream in addition to the pre-existing referral pathway for CPP patients, largely via general practitioners (GPs) and Pain Consultants both within the hospital and from other pain clinics in the region. Further work is required to aid the patient journey from both primary care and gynaecology and obstetrics services into pain services where appropriate.

We then identified a team of PMP clinicians (from the wider and established PMP team) who have special interest in CPP and associated QoL issues. Additional skills and knowledge were developed by visiting other pelvic pain specialists (women's health Physiotherapists, MDT centres, gynaecology clinics and a variety of CPD events). At the point of referral, CPP patients are now triaged to specialist clinicians so that clinical familiarity and expertise can be further developed.

Once referred to the PMP, all patients are screened by a Pain Consultant to ensure all pain medications are optimised and all gynaecological, urological and clinical assessment and management has been adequately pursued. The Canadian Occupational Performance Measure (COPM)¹⁴ records a client's self-perception of performance in everyday living. The measure asks patients to identify and prioritise everyday issues that restrict or impact their performance in daily living. COPM areas were reviewed to ascertain if there were any common themes specific to this group when compared to patients who attend the established PMP for generalised chronic pain. The most commonly reported areas for improvement within the CPP group related to intimate relationships, parenting and the desire to pace and establish a routine. This can be contrasted with the standard chronic pain programme patients who identified common areas for improvement as general activity, walking and personal care.

The value of medical management is not underestimated but the focus of this article will be on patients deemed suitable for a self-management approach in CPP, which usually means that active medical treatment is completed.

Table 1 describes in detail the content of the interdisciplinary pain management assessment completed with all CPP patients referred into the pain service across all disciplines.

Design and delivery of CPP PMP

This specialist PMP for women with CPP was designed to cover all aspects of self-management as described in the BPS's Guidelines (2013).¹⁵ However, the design of the CPP programme incorporates additional aspects across the disciplines to cover topics and themes that are specific to CPP.

The CPP PMP runs for 1 day a week for seven consecutive weeks constituting around 40 hours of faceto-face clinical intervention. Sessions on the CPP PMP are delivered by Clinical Psychologists, Physiotherapists, Occupational Therapists and Pain Consultants. These clinicians have both a specialist interest in CPP and additional training and links with multi-speciality colleagues. Although CPP is not gender specific, the programme caters for a female-only group. This is to encourage more open disclosure regarding salient issues specific to this group such as sexual activity, pregnancy and childbirth.

Specialised content of CPP PMP

The following sections outline the specific roles of each discipline involved in the design and delivery of the CPP PMP; integral to this is the joint planning of sessions to ensure key themes and consistent messages are echoed throughout all sessions.

PMPs are fundamentally a psychologically based intervention. The overarching role of the Clinical Psychologist is to monitor the development of core PMP principles and the progress of the patients throughout the PMP, within a CBT framework. The latter includes formulating the patients' understanding of the self-management approach including how they will continue after the PMP is completed. Specifically within the Clinical Psychology sessions, time is spent understanding the wider impact of CPP and the related psychological distress: the links between thoughts, emotions and behavioural responses. A strong focus is placed on the acceptance of chronic pain and exploring adjustment to life with chronic pain, including the impact of pain on the self and developing a new identity as a person with long-term pain. Specific emphasis within the CPP PMP is placed upon the exploration of the impact of CPP on relationships and sexual function. The Clinical Psychologist facilitating these sessions has additional knowledge and experience of psychosexual therapy approaches, including behavioural and graded approaches to re-engaging with and adapting sexual activity.

Physiotherapy and Medical sessions

The core aim of the Physiotherapy and Medical sessions is to improve management of pain and increase activity despite the pain. Specific attention is given in these sessions to reducing anxiety associated with meaningful and valued activities, achieved through physical exercise sessions and educational workshops. The educational workshops discuss central pain mechanisms and pelvic anatomy using non-medical language; these sessions aim to improve patients' understanding of pain and provide education and reassurance. The Physiotherapist runs further educational sessions discussing posture and flare-up management. It is throughout the posture workshop that patients are encouraged to consider postural changes that they exhibit in response to pain such as guarding and the biomechanical consequences that may be associated with these changes. The CPP PMP timetable also allows discussion of flare-up management and reference is specifically made to menstruation cycles and the fear avoidance cycle.

The physical exercise sessions initially introduce lowintensity exercises with a focus on mindful movement;

Discipline	Assessment			
Medical	 Detailed history and examination to identify reproductive, urologic, gastrointestinal and spinal (neurologic) causes of pain Medical screen to exclude treatable causes, for example, ongoing pathology (infection/inflammation/neoplasm) Educate and support the patient to understand the nature of chronic pain Explain the available treatment options and its paucity Confirm safe and effective use of medical treatment to eradicate or decrease pain, associated distress and disability Introduce the idea of a pain management programme (PMP) early on as part of comprehensive treatment plan to improve symptoms and guality of life (Qol 1) 			
Clinical psychology	 Explore the patient's understanding of their pain condition and their journey through healthcare Readiness to accept chronicity of pain Pain-related distress and disability Patterns of avoidance; cyclical patterns that are common issues in pelvic pain, for example, around emptying bladder or menstruation Communication and relationship patterns Sexual function; conception, pregnancy and disability Thoughts about attending a group programme General goals for a chronic pelvic pain (CPP) PMP Level of psychological flexibility to engage and work independently throughout the weeks of a PMP Coping style Mental health history 			
Physiotherapy	 Understanding of previous management; any relevant urological symptoms to ensure all possible assessment and treatment options have already been explored, or highlight the need for them if required Explore the impact of pain on activity and physical function; to establish patterns, that is, cyclic patterns of activity Assessment questions upon a pelvic bias in addition to a general overview with respect to their pain. For example, patients will be asked if they encounter any issues relating to bladder and bowel activity/function and sexual function/activity 			
Occupational therapy	 The Canadian Occupational Performance Measure (COPM) is used to explore the impact of pain on functioning in daily life and generate client-centred functional goals for attending a CPP PMP Identify patterns in activity, for example, cyclical patterns and explore flare-up management 			

Table 1. Key areas for assessment across the multidisciplinary team.

additional time is spent teaching pelvic floor exercises within these sessions in contrast to the general PMP run by the centre. Once a consistent and confident approach to exercise is established with the patients, alternative exercise options such as use of a gym ball, pilates and hydrotherapy are introduced; functional activities such as sexual relations are discussed openly within sessions.

Occupational Therapy

The core aim of the Occupational Therapy (OT) sessions is to explore the impact of pain on functioning in daily life and the application of self-management skills. OT led workshops explore the impact of pain on lifestyle balance, values, communication and vocational activities. Values are explored in the context of Acceptance and Commitment Therapy (ACT)¹⁶ in which values have been described as 'statements about what we want to be doing with our life: about what we stand for, and how we want to behave on an ongoing basis'. The CPP PMP places emphasis on target setting and activity management; these sessions are delivered jointly with a Physiotherapist. A key component of target setting in the OT sessions is linked with the exploration of patient values covered in the psychology sessions; to aid patients to develop meaningful target areas, they are encouraged to consider meaningful and consistent value-led activity. The OT delivering the CPP PMP is responsible for introducing and practising mindfulness; mindfulness is described as 'paying attention in a particular way, on purpose, in the present moment and non-judgementally'.17 The mindfulness sessions comprise of patients experimenting with monitoring and challenging avoidance, while also supporting them to reconnect with a specific focus on the pelvic area. The latter skill, including increased psychological awareness, is reinforced in workshops facilitated by other disciplines delivering the PMP.

Outcome measures

A range of psychological and physically based outcomes were assessed with the following measures at initial assessment (prior to group allocation), post-PMP and at 6-month follow-up:

- Depression (Beck Depression Inventory-II (BDI-II)).¹⁸ The BDI-II consists of 21 items to assess the intensity of depression in clinical and non-clinical populations. Each item is a list of four statements arranged in increasing severity relating to a particular symptom of depression with total scores ranging from 0 to 63 (higher scores indicating greater severity of depression)
- Pain Catastrophising (Pain Catastrophising Scale (PCS)).¹⁹ The PCS is a 13-item self-report measure designed to assess catastrophic thoughts or feelings accompanying the experience of pain. Respondents are asked to reflect on past painful experiences and to indicate the degree to which each of the 13 thoughts or feelings are experienced when in pain. The questionnaire uses a 5-point scale ranging from 0 (not at all) to 4 (all the time); the scale is rated from 0 (low catastrophising) to 52 (high catastrophising)
- Pain-related anxiety (Pain Anxiety Symptoms Scale (PASS)).20 The PASS was developed to assess anxiety related specifically to pain. It is a short version of the PASS that measures latent, nonspecific pain-related anxiety (e.g. I worry when I am in pain). Each item is responded to using a 6-point Likert-type scale anchored from 0 (never) to 5 (always). The PASS and the PASS-20 assess four distinct aspects of painrelated anxiety. These include the following: (1) Cognitive Anxiety (e.g. I can't think straight when in pain), (2) Pain-related Fear (e.g. pain sensations are terrifying), (3) Escape and Avoidance (e.g. I try to avoid activities that cause pain) and (4) Physiological Anxiety (e.g. pain makes me nauseous). The scale is rated from 0 (low-pain-related anxiety) to 100 (highpain-related anxiety).
- *COPM*.¹⁴ The COPM is an individualised measure of a client's self-perception of problems encountered in daily activities. The COPM was developed to enable individuals to identify every-day issues that restrict or impact upon their daily activities. It has a broad focus on performance in all areas of an individual's life. The COPM is divided into two subscales: performance (rated

from not able to perform (1) to can perform as well as able (10)) and satisfaction (rated completely dissatisfied (1) to completely satisfied (10)).

- Pain-related Self-Efficacy (Pain Self-Efficacy Questionnaire (PSEQ)).²¹ The PSEQ is a 10-item questionnaire developed to assess the confidence people with ongoing pain have in performing activities while in pain. The PSEQ is applicable to all persisting pain presentations, covering a range of functions, including household chores, socialising, work, as well as coping with pain without medication. The scale is rated from 0 (low-pain-related self-efficacy) to 60 (high-pain-related self-efficacy).
- Roland and Morris Disability Questionnaire (RMDQ).^{22,23} The RMDQ is a measure of disability where greater levels of disability are reflected by higher numbers on a 24-point scale. Patients are asked to read the list of 24 sentences and place a tick against those that describe how they feel today. The scale ranges from 0 (low disability) to 24 (high disability).
- Chronic Pain Acceptance Questionnaire (CPAQ).^{24,25} The CPAQ was originally constructed as part of the development of an acceptance-oriented treatment approach for pain patients. Scores from the CPAQ are made up of two components: (a) activity engagement and (b) pain willingness. The scale is rated from 0 (low acceptance) to 120 (high acceptance).
- Numerical Rating Scales Pain Intensity and Pain Distress.²⁶ Pain intensity is rated from 0 (no pain) to 10 (the most intense pain imaginable), taking into account how you have felt over the last week. This commonly used method of rating pain intensity is reliable and valid.²⁵ Pain distress is rated from 0 (no distress) to 10 (extremely distressed), taking into account how you have felt over the last week.
- Repeated sit to stand (1 minute) and 5-minute walk (distance walked within this time). In a research work by Harding et al.,²⁷ the 5-minute walk and 1-minute sit-to-stand task were found to be some of the most useful and sound outcome measures for chronic pain patient's physiotherapy assessments.

Clinically important change analysis

There has been much debate about the difference between statistically significant change and clinically important change and the value of each in examining the efficacy of interventions. This article will use the definition of clinically important change as a change that is noticeable and of value to the patient and health

	Pre-CPP PMP	Post-CPP PMP	6-month follow- up (post-CPP PMP)	Number of patients achieving clinically important change pre- and post-CPP PMP
Beck Depression Inventory	25.6 (9.7)	15.3* (6.9)	7.6* (7.4)	8*
Pain Intensity Numerical Rating Scale	6.8 (1.8)	7 (1.6)	6.1 (1.1)	0
Pain Distress Numerical Rating Scale	7 (2.1)	4.7 (1.6)	4.6 (1.6)	6
Roland & Morris Disability Questionnaire	12.5 (6)	8.3 (4.9)	7.25 (4.6)	4
Pain Catastrophising Scale	29.6 (7)	15.4 (8.9)	13.25 (11.2)	4
Pain Self-Efficacy Questionnaire	24.1 (11.9)	32.4 (3.6)	38.5 (6.6)	6
Pain Anxiety Symptom Scale				
Cognitive Anxiety	17.2 (4.1)	11.6 (4.9)	11.5 (5)	3
Fearful Appraisal	8.6 (5.1)	5.22 (2.3)	3.88 (3.4)	1
Escape/Avoidance	13.8 (5.1)	10 (3.2)	9.4 (3.5)	3
Physiological Anxiety	11.6 (6.6)	7 (3.8)	6.3 (3.3)	2
Total	51.1 (18.6)	33.8 (12.6)	31 (13.3)	2
Chronic Pain Acceptance Questionnaire				
Activity Engagement	33.9 (11.1)	46 (9.1)	40.3 (16.3)	3
Pain Willingness	24.4 (5.8)	27.7 (5.9)	33.1 (7.1)	1
Total	58.3 (13.8)	73.7 (12.1)	73.4 (20.6)	2
Canadian Occupational Performance Meas	sure			
Performance	3.9 (1.6)	7 (1)	7.5 (1)	7
Satisfaction	2.7 (1.7)	7.1 (1)	7.6 (1.2)	9
Sit to Stand	10.8 (7.7)	16.9 (7.5)	19.6 (7.3)	9
5-Minute Walk	211 (129.3)	339 (107.1)	383 (80.5)	8

Table 2. Mean scores (standard deviations) pre-, post- and 6-month follow-up for psychometric measures and physical function measures including number of patients achieving clinically important change (n=9 apart from starred items where n=8).

professional, and that is unlikely to be due to chance.²⁸ In this article, either a reduction or improvement by at least one third of the measures' total value is considered a clinically important change in individual outcome.

Preliminary results

In total, nine females, with an average age of 30 years, diagnosed with CPP attended the first CPP PMP at the start of 2014. In the context of the low number of patients for which outcome data were collected, data were not analysed for statistically significant changes at the level of the group (paired *t*-tests). Table 2 presents the mean scores and standard deviations for each outcome measure described, both pre- and post-intervention. The 6-month follow-up data are also presented. The percentage of patients achieving clinically important change from pre- to post-CPP PMP is noted in Table 2. Clinically important change was defined as an improvement or reduction by at least one third of the outcome measures described.

In order to make some comparison of outcomes on the CPP PMP with our general PMPs, the BDI-II outcomes were analysed for clinically significant outcomes to identify change at the level of the individual. The Initiative on Methods, Measurement and Pain Assessment in Clinical Trials (IMMPACT)²⁹ propose that an initial benchmark for an estimate of clinically important change on the BDI-II in chronic pain trials is a change of five points. Eight (88.8%) of CPP patients who attended the CPP PMP achieved a reduction of their BDI-II (depression) scores by at least five points. We compared this with data collated and analysed in our 2013 service evaluation of outcomes across generalised PMPs (n=215) which found that 60.1% of patients achieved a reduction of at least five points on the BDI-II.

Patient feedback

Patients on the CPP PMP were encouraged at the end of the intervention to provide feedback about their experience on the PMP. In response to '*what helped you the most?*' most patients noted that it was helpful to be in a group with others with the same pain condition, and that they felt both validated and normalised in their response to the impact of living with CPP. Patients also valued the opportunity to discuss the impact of pain on female-related health topics, which are not part of the general PMP.

Discussion

The aim of this article was to describe the development and delivery of a CBT-based PMP for women with CPP. The delivery of the first CPP PMP at The Walton Centre demonstrated that results compare favourably to the established PMP for generalised chronic pain. Specifically, reductions were noted in all patients attending the CPP PMP for all aspects of psychological distress and pain-related disability. The clinical reflections of the team were that these initially favourable outcomes and the positive qualitative feedback from patients may be attributable to a number of factors including: (1) the specificity and relevance of sessions for this patient population, such as discussion of areas of intimacy and sexual function and focus of the physiotherapy sessions on the pelvic area; (2) the value of joint working across disciplines to ensure consistent information provision for the group members; (3) the opportunity for women with CPP to be in a group with others with similar diagnoses, aiding validation, encouragement and support for these patients in improving their OoL; and (4) expert and specialised knowledge of CPP within the clinicians responsible for delivering the CPP PMP.

The development of a CPP PMP for women represents a clear step towards the delivery of specialised interdisciplinary chronic pain management services. These steps are guided by the pathways mapped out by the BPS (Pelvic Pain Pathway)¹ and the EAU Guidelines (2013).³

In the conception and design of the CPP PMP, it was considered fundamental to establish multi-speciality links between a Specialist Pelvic Pain service and Uro-Gynaecology services. Furthermore, there is also a need to facilitate the understanding of chronic pain management within a biopsychosocial approach, which moves away from the organ-/disease-specific model of management in secondary-care services. These multispecialty links facilitate the patient journey from secondary-care services to tertiary care services, which ultimately aids patient engagement accessing effective pain management support and advice.

PMPs are a long-established and well-evidenced treatment for the management of chronic pain conditions. Through interdisciplinary collaboration, it appears that there is value in specialising these programmes to address and accommodate specific issues that may impact upon this CPP presentation. Initial patient feedback suggests that it was helpful to receive treatment in a group of women with similar diagnoses. The results are suggestive that through providing the opportunity for females with CPP to receive their rehabilitation within a same-sex environment, sensitive topics around sexual function and female healthrelated issues (e.g. menstruation, pregnancy and childbirth) can be discussed openly and frankly, the latter supporting an important therapeutic aspect of pain management which is normalising and validating of patients' experiences.

Limitations

Current results are preliminary in nature as the service has completed the delivery of only one CPP PMP. Moreover, the results are limited in size and lack statistical robustness in order to draw specific conclusions. Therefore, outcome review is ongoing and will continue with the completion of further programme evaluation. Additionally, we intend to prepare a further follow-up paper on specific quantitative outcomes (including longitudinal analysis) when sufficient data to analyse with statistical robustness has been achieved. Qualitative research in the areas of sexual function and intimacy will also be included, which are clearly salient to this patient population.

Conclusion

Preliminary results suggest that there is value in delivering a specialised interdisciplinary PMP for patients with CPP particularly in cases where pain management remains problematic following standard care. There is a clear need for further development and clinical research into the effectiveness of multi-speciality and interdisciplinary pain management approaches in CPP. Additional work should also consider the referral processes of patients with CPP and how this impacts upon the patient journey in receiving appropriate and timely care. With respect to the latter, the development of multi-speciality links and clinics may aid the early identification of those CPP patients who may benefit from specialised management including possible inclusion on a CPP PMP.

Declaration of Conflicting Interests

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