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Original Research

## Engaging Patients and Clinicians in Establishing Research Priorities for Gestational Diabetes Mellitus

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### ABSTRACT

**Objectives:** We involved patients and clinicians in Alberta, Canada, to establish research priorities in gestational diabetes mellitus (GDM), using an approach based on a model proposed by the James Lind Alliance (JLA).

**Methods:** We adapted the 4-step JLA process to engage women with GDM and clinicians to identify uncertainties about the management of GDM. Uncertainties were identified through a survey and a review of the clinical practice guidelines (CPG). Uncertainties were short-listed by a steering committee, followed by a 1-day facilitated workshop using a nominal group format and involving a similar number of patients and clinicians, who identified the top 10 research priorities.

**Results:** Across the various survey formats, 75 individuals submitted 389 uncertainties, the majority (44; 59%) coming from patients. We removed 9 questions as being out of scope or unclear, and 41 were identified on a review of CPG, resulting in a total of 421 uncertainties. After the priority setting process, the final top 10 research priorities included questions about a simpler, more accurate and convenient screening test; risk factors for GDM; improving postpartum diabetes screening; the impact of GDM on the future health of the children; lifestyle challenges and mental health issues; safety, effectiveness and/or impact of diet and/or medication treatments; appropriate timing for delivery; and how care is provided, organized or communicated.

**Conclusions:** These top 10 research priorities were informed through a comprehensive and transparent process involving women who have experienced GDM as well as clinicians, and they may be regarded as research priorities for GDM.

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### R É S U M É

**Objectifs :** Nous avons fait participer les patientes et les cliniciens de l'Alberta, au Canada, à l'établissement des priorités de recherche sur le diabète sucré gestationnel (DSG) à l'aide d'une approche fondée sur un modèle proposé par la James Lind Alliance (JLA).

**Méthodes :** Nous avons adapté le processus en 4 étapes de la JLA pour faire participer les femmes atteintes du DSG et les cliniciens à la détermination des incertitudes concernant la prise en charge du DSG.

Une enquête et un examen des lignes directrices de pratique clinique (LDPC) ont déterminé les incertitudes. Après la présélection des incertitudes par le comité directeur, un atelier dirigé d'une journée qui utilisait la technique du groupe nominal et qui comportait un nombre similaire de patientes et de cliniciens ayant déterminé les 10 principales priorités de recherche a suivi.

#### Mots clés :

incertitudes cliniques  
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priorités de recherche

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<sup>1</sup>Patient participants.

**Résultats :** Dans les différentes versions d'enquêtes, 75 individus ont soumis 389 incertitudes, dont la majorité (44; 59 %) venait des patients. Nous avons retiré 9 questions qui étaient hors cadre ou obscures, et en avons relevé 41 lors de l'examen des LDPC, ce qui a donné lieu à un total de 421 incertitudes. Après le processus d'établissement des priorités, les 10 priorités ultimes de recherche comportaient les questions concernant un test de dépistage plus simple, plus précis et pratique; les facteurs de risque du DSG; l'amélioration du dépistage du diabète après la grossesse; les répercussions du DSG sur la santé future des enfants; les difficultés liées au mode de vie et les problèmes de santé mentale; l'innocuité, l'efficacité et/ou les effets du régime et/ou des traitements médicamenteux; le moment opportun de l'accouchement; la façon dont les soins sont fournis, organisés ou communiqués.

**Conclusions :** Ces 10 principales priorités de recherche qui s'appuyaient sur un processus exhaustif et transparent comportant des femmes atteintes d'un DSG ainsi que des cliniciens peuvent être considérées comme étant les priorités de recherche sur le DSG.

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## Introduction

Interest in engaging patients, an overarching term that includes individuals with personal experience of a health condition and informal caregivers, such as family and friends, in the design, conduct and translation of health research, has grown substantially in developed countries over the past 15 years (1–4). Between 1995 and 2009, the number of research publications concerning patient engagement in the research process has increased from 95 to more than 680, with many new projects continuing to be added to the field (2). Through their lived experience with an illness, condition or situation, patients provide unique perspectives into research, suggesting research outcomes that may be more effectively applicable to patient care (4).

With the growing recognition that patients should be more involved in research, efforts to engage patients in the establishment of research priorities have expanded. The James Lind Alliance (JLA), established in 2004 in the United Kingdom (UK), has developed a structured method of engaging patients and clinicians so as to determine their views about topics that require more research and to prioritize them for incorporation into the research agenda (5). The 4-step process is based on the principles of fairness and transparency, and it brings clinicians and patients together to determine jointly the research priorities that are important to them (5). This process has been used for a variety of conditions in the UK, including asthma, vertigo and type 1 diabetes, and has also been used in Canada for end-stage renal disease (5,6). Patients' and clinicians' research priorities have never before been determined for GDM in this way. A significant increase in the incidence of GDM in the province of Alberta, Canada, from 3.1% in 2000 to 4.6% in 2009, made this condition an ideal topic to pilot an adaptation of the JLA process (7).

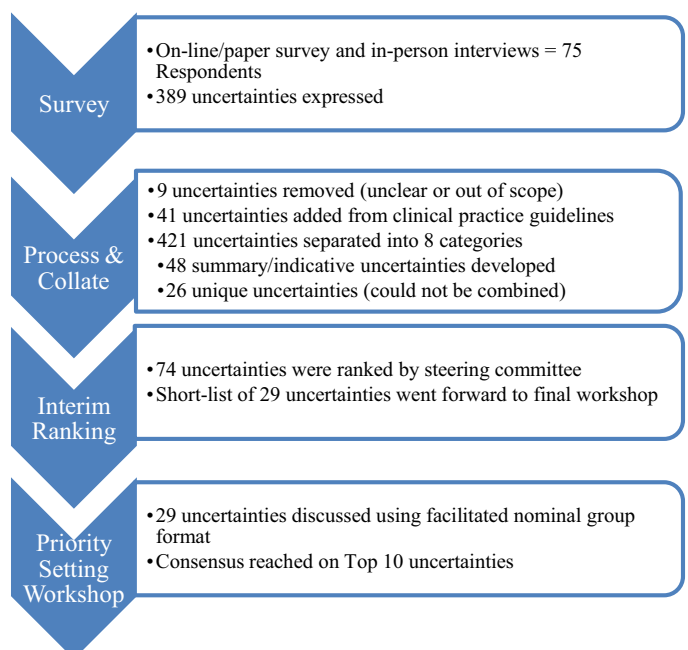
Gestational diabetes mellitus (GDM) is glucose intolerance that is first recognized during pregnancy, typically after 20 weeks of gestation (8). Although GDM is considered a temporary condition and commonly resolves postpartum, it is also an established risk factor for the subsequent development of type 2 diabetes by the mother (8). In Canada, 19% of women with GDM developed type 2 diabetes by the 9th year postpartum, and it is estimated that the risk for diabetes may be as high as 50% to 60% within 15 years postpartum, nearly 10-fold the risk in the general population (8–11). In addition to a higher risk for diabetes, women with GDM also have an increased risk for developing cardiovascular disease later in life (12). Similarly, the offspring of women with GDM can have an increased risk for obesity and glucose intolerance in adolescence and young adulthood, respectively (13–14). Thus, in addition to being an entity that must be managed during pregnancy, GDM is an important marker of a high-risk status for future diabetes and all its serious health-related complications for both the mothers and the children. We adapted the JLA process in order to determine the research priorities of women who had experienced GDM and the clinicians who provide care for them.

## Methods

In the JLA process, a priority-setting partnership and steering committee are established, and management uncertainties are gathered, processed and collated into a short list, which is considered at a face-to-face workshop, where the final top 10 list is chosen. We adapted this process as outlined below (Figure 1).

We established a steering committee consisting of 3 patients and 3 clinicians (1 family physician who practises intrapartum care, an endocrinologist and a neonatologist); a facilitator familiar with the JLA process (AL) and a project manager (SR). The steering committee held 1 in-person meeting at the start of the project, followed by telephone meetings every 2 weeks for the duration of the process (June 2014 to February 2015).

Uncertainties were collected by a survey consisting of 10 open-ended questions and 7 demographic questions (available on request from the authors). The open-ended questions asked for broad information about the stages of GDM management, including screening, treatment, lifestyle concerns, care provision, labour and delivery, care of the newborn, future health, communication and overall management. Demographic questions asked respondents' perspectives (Table 1), ages, gender, whether the respondents were born in Canada, ethnicities, annual household incomes and the first 3 digits of their postal codes. After pilot testing the survey with a small group of patients, separate surveys were prepared for patients and



**Figure 1.** Summary of priority setting process for determining top 10 priorities.

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