

Health research — synthesized and contextualized for use in Newfoundland & Labrador

# Patient Decision Aids in Obstetrics in Newfoundland & Labrador

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## **About This Report**

## About NLCAHR

The Newfoundland and Labrador Centre for Applied Health Research, established in 1999, contributes to the effectiveness of the health and community services system of the province and the physical, social, and psychological wellbeing of the population. NLCAHR accomplishes this mandate by building capacity in applied health research, supporting high quality research, and fostering more effective use of research evidence by decision makers and policy makers in the province's health system.

## About the Contextualized Health Research Synthesis Program

In 2007, NLCAHR launched the Contextualized Health Research Synthesis Program (CHRSP) to provide research evidence that would help guide decision makers in the provincial health system on issues of pressing interest to Newfoundland and Labrador. Instead of conducting original research, CHRSP analyzes findings from high level research already conducted in the subject area, such as systematic reviews, meta-analyses and health technology assessments. Findings are then synthesized and subjected to a systematic process of contextualization: they are analyzed in terms of their applicability to the conditions and capacities of the unique context of Newfoundland and Labrador. Our contextual analysis includes assessing the specific forms an issue may take in this province as well as the

applicability of any proposed solutions and methods to locally available resources, infrastructure, human resources, cultural conditions and financial capacities. CHRSP uses a combination of external experts and local networks to carry out and contextualize the research synthesis and to facilitate the uptake of the results by research users. CHRSP focuses on three types of projects: health services/ health policy projects, health technology assessment (HTA) projects, and projects that combine the two to examine processes for the organization or delivery of care involving a health technology.

## Who Should Read This Report?

This report provides a synthesis of the relevant research-based evidence on the effect of Patient Decision Aids on knowledge and decisional conflict when engaging in shareddecision making within the childbearing year. This report is intended to support decision makers in Newfoundland and Labrador's four **Regional Health Authorities and the** Departments of Health and Community Services and of Children, Seniors and Social Development. The findings of our synthesis are based on an international search of the literature and may also be applicable to other jurisdictions in Canada and elsewhere, but are specifically interpreted for the context of Newfoundland and Labrador. The report includes explanations of research terms and technical language so that there is no need to have a specialized medical or health background in order to understand its content.

## The Research Team

### Patient Decision Aids in Obstetrics in Newfoundland & Labrador

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## Acronyms

AMSTAR	Assessment of Multiple Systematic Reviews
CADTH	Canadian Agency for Drugs and Technology in Health
CHRSP	Contextualized Health Research Synthesis Program
CINAHL	Cumulative Index to Nursing and Allied Health Literature
DAT	Decision Analysis Tools
DC	Decisional Conflict
ERS	Evidence Rating System used for CHRSP
НСР	Health Care Provider
HTA	Health Technology Assessment
NL	Newfoundland & Labrador
NLCAHR	Newfoundland and Labrador Centre for Applied Health Research
PDA	Patient Decision Aid
RCT	Randomized Controlled Trial
SDM	Shared Decision-Making
SR	Systematic Review
PR	Primary Research
VBAC	Vaginal Birth after a Caesarean Section

## Glossary

AMSTAR (Assessment of	An 11-item instrument used to assess the methodological rigour of
Multiple Systematic Reviews)	systematic reviews.
Anesthesiologist	A physician who has special training in providing drugs or other
	agents to prevent or relieve pain during surgery or other
	procedures; a doctor who practices anesthesia. Anesthesiologists
	specialize in perioperative care, developing anesthetic plans, and
	the administration of anesthetics.
Breech Presentation	The situation in which a fetus is in a longitudinal lie with the
	buttocks or feet closest to the cervix (1).
Caesarean Delivery	A surgical procedure used to deliver a baby through incisions in the
	abdomen and uterus.
Childbearing year	The period of time that begins at conception and ends at birth.
Decisional Conflict	A state of uncertainty about the preferred course of action. It is
	most prevalent regarding choices involving outcomes that are risky
	or uncertain, that have the potential for high stakes gains and/or
	losses, and that may create feelings of anticipation of regret over
	rejected options (2–4).
Geographical Distribution of	The number of inhabitants in, or spread across, designated
the Population	subdivisions of an area, region, city or country.
Health Care Providers	Under Canadian federal regulations, a "health care provider" is
	defined as: a doctor of medicine or osteopathy, podiatrist, dentist,
	chiropractor, clinical psychologist, optometrist, nurse practitioner,
	nurse-midwife, pharmacist, or a clinical social worker who is
	authorized to practice.
Health Literacy	The degree to which individuals have the capacity to obtain,
	process, and understand basic health information needed to make
	appropriate health decisions.
Heterogeneity	The differences in the populations, samples, results, interventions,
	and/or the control groups analyzed in multiple systematic reviews.
High-Risk Pregnancy	Any pregnancy that carries increased health risks for the pregnant
	person, fetus (unborn baby) or both. People with high-risk
	pregnancies may need extra care before, during and after they give
	Dirth.
Labour Analgesia	childhirth, and the only method that provides complete analysis
	without maternal or fatal sodation
Location of Dolivery	Any region or facility in which program horsens can give high This
Location of Delivery	Any region or facility in which pregnant persons can give birth. This
	can mean geographic location, such as rural or urban areas, and
Midwifory	The profession or practice of assisting program persons in
witawitery	childhirth
Obstatrician	A physician or surgeon qualified to practice in obstatrics
Obstetriciali	A physician of surgeon quanned to practice in obstethts.

Obstetrics	The branch of medicine and surgery concerned with childbirth and		
	the care of patients giving birth.		
Obstetrical Care	Obstetrical care involves medical services, nursing services, and		
	health-related services provided throughout pregnancy, labor,		
	delivery, and postpartum.		
Obstetric Services	Obstetric services include any normal or high-risk services provided		
	in an acute care hospital to the mother and fetus during pregnancy,		
	labor, delivery, and to the mother after delivery.		
Paternalistic Healthcare	When a physician or other healthcare professional makes decisions		
	for a patient without the explicit consent of the patient based on		
	the belief that the physician's decisions are in the patient's best		
	interests.		
Patient-Centered Healthcare	Providing care that treats patients with dignity and respect and		
	involves them in all decisions about their health. Patient-Centred		
	Healthcare is responsive to individual patient preferences, needs		
	and values (5).		
Patient Decision Aid (PDA)	A Patient Decision Aid (PDA) is a tool that facilitates and promotes		
	the shared decision-making process and that takes into account		
	patient values and priorities alongside clinical considerations		
	(2,3,6). PDAs are used to support complex decisions where		
	scientific evidence about the available options might be limited (7).		
Patient Decision Aid Format	PDA Format refers to the medium in which the PDA is delivered		
	(e.g., online information, printed materials, verbal communication,		
	etc.)		
Post-partum	Following childbirth or the birth of young; a period of time after		
Due en en Conservice	Childbirth.		
Pregnancy Scenarios	The scenarios in which people have to make decisions about their		
Dropotol Tosting	The two main types of proposal testing are:		
Prenatal resting	The two main types of prenatar testing are.		
	Screening tests that identify whether the baby is more of less likely to have contain birth defects, many of which are constic		
	disordors. Those tests include blood tests, a specific type of		
	ultracound, and proposal coll free DNA screening. Proposal		
	coreaning tests are usually offered during the first or second		
	trimostor. Screening tests cannot make a definitive diagnosis. If		
	results indicate an increased rick for a genetic dicorder, the		
	health care provider will discuss options for a diagnostic test to		
	confirm the diagnosis		
	<ul> <li>Diagnostic Tests are used if a screening test indicates a possible</li> </ul>		
	problem — or if their age, family history, or medical history		
	nuts natients at increased risk of having a haby with a genetic		
	nrohlem In such scenarios the nationt might consider an		
	invasive prenatal diagnostic test as the only way to confirm a		
	diagnosis. Some diagnostic tests, such as chorionic villus		
	sampling and ampiocentesis carry a small risk of miscarriage		
Primary Care	Care from the main healthcare professional treating vou—		
	usually a general practitioner, nurse practitioner. or internist		

Rural	For purposes of this report, we have used the Newfoundland and
	Labrador Statistics Agency definition of rural as being any area
	outside the Census Metropolitan area, the four Census
	Agglomerations, or outside of communities with a population of
	over 5,000.
Secondary Care	Secondary care often involves the referral of a patient to a
	specialist at a hospital for closer assessment or treatment.
Shared Decision Making	A process in which both the patient and healthcare professional
	work together to decide on the best plan of care for the patient,
	while the patient's values, goals, and concerns are considered.
Tertiary Care	Tertiary care is a level above secondary care that is defined as
	highly specialised medical care, usually provided over an extended
	period of time, which involves advanced and complex diagnostics,
	procedures and treatments performed by medical specialists in
	state-of-the-art facilities.
Usual Care	While the controls in studies related to Patient Decision Aids are
	often referred to as "usual care," what actually constitutes usual
	care is often defined vaguely or highly variably in the literature. For
	the purposes of this report, some examples of usual care are:
	discussing options with a health professional, educational
	materials, such as a standard pamphlet or booklet, and counselling.
Vaginal Birth after Caesarean	A situation in which pregnant persons have a vaginal birth after
Section (VBAC)	having had a Caesarean Section in a previous pregnancy.

## The CHRSP Approach to Health Evidence

What is Health Evidence? Health evidence comes in a variety of forms that depend on the methodology of the research and other factors. Researchers may use quantitative (collecting, analyzing and interpreting numerical data), qualitative (collecting, analyzing, and interpreting non-numerical data) or mixed-methods approaches (a combination of quantitative and qualitative methods). The methodological rigour of a given study will have an impact on the reliability and generalizability of the results.

The most reliable form of health evidence to inform healthcare decision making is the systematic review. A systematic review uses systematic and reproducible methods to identify, select and critically appraise numerous primary studies on a given topic. The authors collect and analyse data from the studies that are included in the review to answer a focused research question. CHRSP focuses on this high-level category of health evidence, taking the results from multiple systematic reviews into consideration.

Locating, Assessing, and Synthesizing Evidence: CHRSP researchers, working with a health sciences librarian, devise an appropriate search strategy and conduct rigorous electronic and hand searches of periodical indices and databases to locate relevant health evidence which will include high-level research (systematic reviews, meta-analyses, and health technology assessments) and high-quality primary studies that were published too recently to have been included in the review literature. Evidence may also include relevant unpublished literature, government documents, etc. known as "grey literature." Once the relevant research materials have been collected, the team critically appraises and summarizes the evidence in terms of its quantity (i.e., we assess whether there is ample evidence on which to base a report) and its quality (i.e., we rate its methodological rigour using validated assessment tools). CHRSP also assesses the strength of the findings using an Evidence Rating System that tells us about the reliability of the body of evidence for a given intervention to produce a given outcome. The results are then synthesized into a series of key findings from the evidence, a phase of the CHRSP project that tells decision makers "what works," according to the published evidence.

**Setting the Evidence in Context**: Once we have assessed what the evidence has to say about "what works," we ask a further question: "Would that work *here*?" recognizing that local contextual variables must also be considered when making decisions in healthcare. Contextual factors may increase or decrease the positive health impacts or cost-effectiveness of an intervention that was reported in the research literature. These variations in effectiveness result from differences between the research settings and local conditions in Newfoundland and Labrador. For instance, interventions that work well in large urban centres with a large number of specialists and adequate health human resources may not translate well into a rural Newfoundland setting where access to specialized care is limited. The CHRSP Project Team therefore tailors its syntheses to the local context at every stage of its projects. Key contextual considerations may include: patient populations, sites of service and/or the service design, health human resources, organization and delivery of services, health economics, and politics.

**Interpreting the Evidence:** Once the literature has been located, assessed, synthesized, and contextualized, the CHRSP Project Team will then develop a summary of considerations for decision

makers to think about when applying the evidence for use in Newfoundland & Labrador. CHRSP recognizes that the research evidence is one of several factors that health system decision makers need to consider when they make decisions; therefore, our reports present key issues for decision makers to *consider* as opposed to making any assertions about which options they should *choose*.

## The Research Question

"How do Patient Decision Aids affect patient knowledge and decisional conflict when patients and their caregivers engage in shared decision making within the childbearing year?"



The following key messages summarize the most relevant findings from this report and reflect the state of the available research evidence on this topic:

- 1. The research evidence suggests that Patient Decision Aids tend to improve patients' knowledge of obstetrics topics.
- 2. The research evidence suggests that Patient Decision Aids tend to reduce patients' uncertainty (decisional conflict) about the preferred course of action in pregnancy.
- 3. Findings about patients' anxiety and satisfaction after using Patient Decision Aids are mixed, with some research suggesting improvements (i.e., reduced anxiety and greater satisfaction), and other research indicating no effect on these outcomes.
- 4. Little evidence was found for the outcome of informed decision making; however, the limited research that is available suggests that Patient Decision Aids lead to better-informed patient decisions.
- 5. While most of the formats of Patient Decision Aids reviewed in this report are effective, our synthesis indicates that computer-based Patient Decision Aids are the most effective.
- 6. Patient Decision Aids are consistently effective in most pregnancy scenarios reviewed in this report, except when used for decisions about prenatal screening.

## How to Navigate this Report

- The section of this report entitled **Synthesis Findings** provides supporting detail about each of the preceding key messages. This section provides readers with a comprehensive overview of the scientific evidence that was examined for this study.
- Local contextual variables that may have an impact on how decision makers apply the evidence in Newfoundland and Labrador are detailed in this report under the section: The Newfoundland and Labrador Context.
- The synthesis findings are then considered in light of the contextualization findings to develop a list of **Considerations for Decision Makers**. Please note that CHRSP prefers to use the term "considerations" rather than "recommendations" because we recognize that research evidence is one of many inputs that health system decision makers may need to consider. This section of the report presents some of the issues decision makers should *consider* rather than asserting any particular options they should *choose*.

## Background

Increasingly, healthcare decision makers, clinicians, and patients have come to expect that obstetrical care will involve shared decision making, a process in which healthcare decisions are shared between patients and their care providers (2,4). Having a shared decision making model in place can help ensure that patients understand their available options; are aware of the risks and benefits of these options; and are able to incorporate their personal values, preferences, and concerns when making informed decisions about their own care (4,8).

Pregnant people may face many important decisions that require them to understand and to consider risk, whether the risk is to the parent or to the fetus. In rural and remote areas, obstetrical decisions related to risk are often compounded by concerns about the social and cultural impacts of having to leave one's home community and family during a time when family and community supports can be crucial. As a result, obstetrical decision making often causes considerable anxiety and uncertainty ("decisional conflict"), particularly when diverse and sometimes competing priorities must be reconciled.

Research suggests that models of shared decision making that incorporate a patient's personal needs and values can mitigate decisional conflict and tension (2,4,9). Growing research evidence also points to the importance of healthcare providers in decision making – as healthcare providers can supply evidence and information that will assist the pregnant person in the decision-making process during all stages of pregnancy, including preparation for birth and for the post-partum period (10). Overall, obstetrical care is improved when clear and concise evidence-based information is presented through a balanced, comprehensive and standardized approach (11). One such approach to shared decision making is known as *Patient Decision Aids*.

Patient Decision Aids (PDA) are tools that facilitate and promote shared decision making by taking into account patient values and priorities alongside any clinical considerations (2,3,6). They are especially useful in supporting complex decisions in cases where the scientific evidence about available options might be limited (7). Some goals of Patient Decision Aids are to:

- provide unbiased, individualized information,
- provide a framework to take into account the patient's values and preferences,
- help people make informed choices,
- reduce anxiety around making choices,
- reduce uncertainty (or decisional conflict),
- increase knowledge about patient's options, and
- ensure patients are satisfied with their final decision (7,12).

Importantly, Patient Decision Aids are meant to facilitate provider guidance, not to replace it, and they are not meant to persuade patients to choose one option over another (9).

## Relevance to Newfoundland & Labrador

As of 2020, 10 hospitals in Newfoundland and Labrador (NL) provided healthcare services for labour and birth: four in Eastern Health, two in Central Health, one in Western Health, and three in Labrador-Grenfell Health (13). The uneven distribution of the population across the province is reflected in the report of birth numbers per region (Table 7) in the year 2020. Birth numbers in this province varied, according to the data provided, from a high of 2,263 in the Eastern Health region to a low of 333 in the Labrador-Grenfell Health region. It is notable that the annual overall birth rate is decreasing in all regions of the province, mostly attributed to a complex set of economic, social, and cultural factors (14).

Obstetrical service delivery in this province varies widely in terms of the capacity to handle certain situations that are related to labour, birth, and newborn care. Not all facilities are equipped to manage certain emergencies or acute clinical conditions. Moreover, the province's widely-dispersed population often necessitates pregnant patients leaving their home communities in order to access higher levels of care. The province's geography can make such journeys both long and arduous, especially in pregnancy. Exacerbating the complexity of these demographic issues are the personal, cultural, or religious reasons that may factor into a given patient's decisions about whether or not to travel for delivery. Ethically, a care provider cannot coerce a patient into choosing a given birth option— nor can the provider abandon patients who may choose a course of action with which the provider disagrees (15).

Communications between expectant parents and their healthcare providers about the location of delivery<sup>1</sup> are therefore an especially significant concern for health system decision makers in NL. Health system decision makers also understand that relocating to give birth may have negative health consequences: for example, pregnant people may have to leave home well before their due date, leaving them isolated from their families and communities for a long period of time. Alternatively, remaining in their home community to give birth may pose clinical risks.

The evidence indicates that patients are more likely to experience a sense of control about their obstetrical care if their healthcare provider engages them in a collaborative process involving effective communication about the risks and benefits of their options, while honouring patient autonomy. As Kotaska (15) notes, following such ethical considerations provides pregnant people with an important opportunity to make informed decisions about their own care and also offers a mechanism through which healthcare providers will not be held liable for outcomes resulting from the decision. Healthcare decision makers in NL are seeking to ensure that communications between healthcare providers and patients provide sound information about the risks and benefits of any possible delivery location choices; that they are clear and understandable for everyone; that they are respectful of the patient's own values and preferences; and that they facilitate shared decision making between patients and their healthcare providers.

With these concerns in mind, our provincial health system partners asked the Contextualized Health Research Synthesis Program (CHRSP) team to examine high-level research evidence that would identify tools to support shared decision-making in the child-bearing year.

In April 2021, CHRSP assembled a CHRSP Project Team that included a subject matter expert, a health system leader, and representatives from Eastern Health, Central Health, Western Health, Labrador-Grenfell Health, Memorial University and the Association of Midwives of Newfoundland and Labrador. In consultation with this Project Team, we arrived at the following research question for this *Evidence in Context* Report:

#### "How do Patient Decision Aids affect patient knowledge and decisional conflict when engaging in shared decision-making within the childbearing year?"

This document reports on the results of this research project. It briefly describes the CHRSP methodology, presents a summary of our search results and knowledge synthesis, and describes the results of our contextualization interviews. Finally, we have developed a series of considerations from our findings that health system decision makers in NL may wish to consider when applying the results.

<sup>&</sup>lt;sup>1</sup> Location of delivery refers to any region or facility in which pregnant persons can give birth. This can mean geographic location, such as rural or urban areas, and the place of birth, such as at home, a birth centre, or in a hospital.

## Methodology

### What evidence did we look for?

In collaboration with a Memorial University Librarian and our Subject Matter Expert, we developed several search strategies to identify eligible systematic reviews (including meta-analyses) in three periodical indexes (PubMed, CINAHL, and Embase). In addition, we located evidence by searching for articles in Google Scholar and by searches for "related articles" within periodical indexes. We also searched for relevant primary research that was conducted too recently to be included in the systematic review literature by searching the same periodical indices and some modified versions of the search strings used in the systematic review search. Finally, we searched for grey literature (i.e., non-commercially published research) by following the most recent version of the CADTH Grey Matters List (please see the Online Companion Document).

#### Search Parameters

With guidance from the project team, including the subject matter expert, we decided on specific parameters to identify the most relevant research evidence. For a research study to be included in the current synthesis, it had to:

- be a systematic review or a meta-analysis covering at least two studies and published within the past 10 years or be a very recent, high-quality primary study;
- include people who were making decisions about their pregnancy within the childbearing year;
- include a comparator group receiving usual care, educational materials, or another intervention;
- study an intervention that followed our definition of a patient decision aid;
- measure outcomes related to knowledge, decisional conflict, satisfaction, anxiety, or perception of making an informed decision; and
- be published in English.

## What evidence did we find?

The following outlines the results of our search and the nature and quality of the evidence we located for this evidence synthesis. We begin with some basic definitions:

- A systematic review is a scientific investigation that focuses on a specific research question and uses explicit, prespecified methods to identify, select, assess, and summarize the findings of a series of similar but separate primary studies.
- **Primary research or a primary study** refers to a research article that is original research that is almost always published in a peer-reviewed journal. A primary study reports on the details, methods and results of a single research study.
- A randomized control trial (RCT) is a study design that randomly assigns participants into an experimental group or a control group. As the study is conducted, the only expected difference between the control and experimental groups in a randomized controlled trial (RCT) is the outcome variable being studied.

Our search identified evidence from 12 systematic reviews (six of which had at least one Canadian study; 3,4,9,16–18) and from five separate primary studies (none of which were Canadian) that were published too recently to have been captured within the review literature. All included systematic reviews restricted their scope to include only randomised control trials. Four of the five primary articles were also RCTs (19–22) the fifth primary study was described as a non-randomized (non-equivalent) controlled trial with purposive sampling (23).

## **Critical Appraisal**

#### Assessing Quality

We use the AMSTAR<sup>2</sup> instrument (the maximum AMSTAR score is 11) to appraise the methodological quality of systematic reviews:

- a score of 0 to 3 indicates a Low Quality Systematic Review;
- a score of 4 to 7 indicates a Moderate Quality Systematic Review; and
- a score of 8 to 11 indicates a High Quality Systematic Review (24).

Of the 12 systematic reviews, five were rated as being of "High Quality" with seven being of "Moderate Quality." Two CHRSP researchers carried out the AMSTAR quality appraisal independently and the interrater reliability was 0.97 which is considered to be high. Table 1 below summarizes the quality appraisal of the evidence in this synthesis.

Methodological Quality	Reference	AMSTAR Score (out of 11)	Was it a Cochrane Review*?
	Stacey 2017 (3)	10	Yes
Llich Quality	Van Agt 2014 (18)	9	No
High Quality	Horey 2013 (16)	8	Yes
(S included reviews)	Vlemmix 2012 (9)	8	No
	Yu 2021 (2)	8	No
Moderate Quality (7 included reviews)	Dugas 2012 (4)	7	No
	Nilsson 2015 (25)	7	No
	Zibellini 2020 (26)	7	No
	Skjoth 2015 (17)	7	No
	Ngo 2020 (27)	5	No
	Poprzecny 2020 (8)	5	No
	Say 2011 (12)	5	No

#### Table 1: Critical appraisal results for eligible systematic reviews

\* **Cochrane Reviews** are systematic reviews of primary literature and are internationally recognized as the highest standard in evidence-based health care.

As noted above, we also located five primary studies that were too recently published to have been included in the systematic review literature. Table 2 below shows the results of our critical appraisal of these studies using the appraisal tool developed by Downs & Black (28). Primary studies scoring 28-26 are deemed to be of excellent quality with scores of 25-20 deemed to be good, 19-15 fair, and less than 14 poor. Note that all five studies included in this report were deemed to be of good quality.

<sup>&</sup>lt;sup>2</sup> AMSTAR (Assessing the Methodological Quality of Systematic Reviews) is a critical appraisal tool for systematic reviews that include randomised or non-randomised studies of healthcare interventions.

#### Table 2: Critical appraisal results for eligible primary studies

Methodological Quality	Reference	Downs & Black Score
	Kuppermann 2020 (20)	23
Good Quality	Hadizadeh-Talasaz 2021 (21)	23
(5 included primary studies)	Guillen 2019 (22)	21
	<b>Chen 2021</b> (19)	20
	Shishido 2020 (23)	20

#### The CHRSP Evidence Rating System

The CHRSP Evidence Rating System assesses the strength of the combined body of evidence about a particular intervention for achieving a given outcome for a defined population. The strength of the body of evidence increases with:

- the quality of the systematic reviews included in the analysis;
- the number of unique primary research studies included within the reviews; and
- the consistency of the findings.

#### Assessing Number of Studies and Consistency

The table below outlines the thresholds for the number of reviews and included primary studies required to determine the strength of the body of evidence. Largely inconsistent findings, regardless of the number and quality of systematic reviews, are interpreted as a "Very Weak" body of evidence by default.

Strength of the Body of Evidence	# of Systematic Reviews	# of Primary Studies included in the review literature
Strong	2 or more High Quality reviews	10+
Moderate	1 or more High Quality reviews	10+
Weak	1 or more High Quality reviews	5+
Very Weak	1 review with moderate or inconsistent findings	1-4

#### Table 3: CHRSP ERS: Evidence thresholds for strength of body of evidence

#### Considering the Impact of an Intervention on an Outcome

The CHRSP Evidence Rating System also considers whether the body of evidence:

- favors the intervention (i.e., the evidence indicates that the intervention works effectively enough to consider implementing it);
- indicates no benefit when the intervention is compared to the control (i.e., the intervention is no better than usual care); or
- is unable to indicate whether the intervention achieves better outcomes than the control (i.e., the report authors cannot draw any conclusions because there is a lack of evidence or there is conflicting evidence).

### **Characterizing the Evidence**

The systematic reviews in this report used common PDA formats and obstetric scenarios to measure the effectiveness of the Patient Decision Aids. We describe below how the systematic reviewers approached and analyzed the differences between the primary articles included in their reviews and how the varying controls that were used may have contributed to differences in the findings among included studies.

#### Describing and defining the Patient Decision Aids included in the literature

Patient Decision Aids are a means of helping people make informed choices about healthcare that take into account their personal values and preferences. Decision aids are a part of a shared decision-making process, encouraging active participation by patients in healthcare decisions. Readers should note that Patient Decision Aids can be used in a variety of contexts to support any number of health-related decisions and are especially effective for decisions where evidence is emerging or equivocal and/or where patient preference may be a significant factor in the decision-making process. Indeed, Patient Decision Aids need to be tailored for individual clinical situations, including contextual influences and target populations.

For the purposes of this report, however, the Patient Decision Aids being considered focus specifically on obstetrics. We looked specifically at Patient Decision Aids that support the shared decisions that pregnant patients have to make. While it is assumed that Patient Decision Aids were used in a shared decision-making context, the detail from the included studies does not make this clear, and it is possible that Patient Decision Aids were simply given to the patients. As well, the systematic review literature is vague as to what degree Patient Decision Aids were used and when during the patient's care they were used.

We found that the systematic reviews and primary studies included in this report did not exclusively look at any single pregnancy-related scenario in which a decision would be required, but rather identified a number of potential pregnancy scenarios. This heterogeneity also extended to the fact that the reviews did not tend to focus on one PDA tool, instead researchers looked at a variety of tools and formats intended to support making decisions.

Since Patient Decision Aids are designed to promote shared decision-making and to facilitate communication, they would be expected, overall, to help improve health literacy and/or facilitate communications between HCPs and populations with low health literacy levels. However, in our review of the literature, review authors noted a lack of research that focuses on health literacy in either the development of Patient Decision Aids or in their evaluation (26,29,30).

#### Patient Decision Aids: Defining the formats

Within the systematic review literature, most authors categorized Patient Decision Aids in terms of the format of their transmission rather than by the content or design of the PDA itself. Common labels given to the PDA formats within the systematic review literature included:

- audio,
- computer-based tools,
- counseling,
- Decision Analysis Tools (DAT),
- paper-based tools, and
- video.

The use of such terms to describe the PDA formats was not consistently applied in the literature and we note that future research would certainly benefit from employing a more consistent set of terms to describe PDA interventions. Below, we explore some of the key inconsistencies to give readers a better sense of how the literature differs in its use of definitions and terms when it comes to Patient Decision Aids.

We found considerable differences of opinion when it came to the nature of Patient Decision Aids provided in paper formats. Most reviews defined paper-based tools (such as leaflets or pamphlets) as Patient Decision Aids, however, some researchers disagreed, with the authors of one high-quality systematic review stating that the difference between a leaflet and a decision aid can be quite pronounced, noting that leaflets are typically designed to provide information/increase knowledge whereas Patient Decision Aids would include extra materials such as exercises that would help patients to clarify their own personal values and preferences (18). While written materials such as booklets were defined in another study as being a form of PDA, the researchers did not consider leaflets, for example, to constitute a PDA (9).

Moreover, the terminology used to describe Patient Decision Aids is inconsistent across studies. The authors of one systematic review did not use the term "decision aid" at all, but preferred to use "decision support tools" (27). Another review used "decision aid" to mean a type of "decision support" (16). Further confusing the definitions, the review that used "decision support tools" referenced several studies that used the term "decision aid" (27). Most importantly, however, some systematic reviews stated that, regardless of the format, a PDA is different from any other intervention because, in addition to listing information about treatments (i.e., identifying the risks and benefits), a PDA must also consider patient's values and preferences (4,7,18).

In those cases where information is shared/ the intervention is delivered by trained counsellors or by any other in-person oral means, the term Counselling Patient Decision Aids was used. "Counselling" itself is a frequent term used in the PDA literature (4,9).

#### Decision-making scenarios

The systematic review literature included different scenarios in which pregnant people had to make decisions. For example, reviewers examined the effect of Patient Decision Aids on making decisions about prenatal testing, breech presentation, the use of labour analgesia, and other decisions that may arise in the child-bearing year. Because the scenarios varied, it is difficult to say definitively whether Patient Decision Aids work better in certain decision-making scenarios (hereinafter referred to as "pregnancy scenarios") than they do in others.

#### Defining the control group

Most of the literature we reviewed compared the PDA to 'usual care.' Usual care refers to the standard of care that the patient would have received prior to/without the new intervention being tested. However, again, we found that definitions were inconsistent and that usual care was not generally well-defined in the literature. Instead, defining usual care depended on factors such as where and when the study was performed, what legislation was in place, the type of healthcare provider, the care providers' philosophy of care, theories and practices considered acceptable, and any number of other situational, contextual, and environmental factors that made direct comparisons very difficult.

Some examples of usual care controls that were compared to the Patient Decision Aids included:

- discussions with a health professional,
- a standard pamphlet or booklet,
- counselling,
- education materials, and/or
- video/audiovisual material.

Controls were usually described as "routine care," "standard care," and "usual care." In some cases, the systematic reviews would identify the controls used in the primary research as "usual care," while other systematic reviews would identify the same controls as something else.

#### The Problem of Heterogeneity

Given the variability among studies included in this report, one major caveat in interpreting the literature on this topic is the high level of heterogeneity among described Patient Decision Aid (PDA) formats, pregnancy scenarios, and study controls. With this level of heterogeneity (populations, samples, results, interventions, and/or the control groups analyzed all being different) it is very difficult to make direct comparisons across studies.

Most systematic reviews made note of this heterogeneity and therefore analyzed the included studies through statistical analyses, generally using the I<sup>2</sup> statistic<sup>3</sup> (2,4,8,9,16). We found a number of key differences among studies when we compared the types of Patient Decision Aids and the decision-making scenarios. For example, the literature names all interventions as "Patient Decision Aids," although a PDA could be in a number of different formats. Readers should be cautioned that a PDA is designed specifically for the decision-making scenario, the setting in which the decision takes place, and the population it is targeting.

## Synthesis Findings for Patient Decision Aids in Obstetrics

In this section, we synthesize the evidence for the effect of Patient Decision Aids on the following patient outcomes:

- patient knowledge,
- decisional conflict,
- patient anxiety,
- patient satisfaction, and
- informed decision making.

<sup>&</sup>lt;sup>3</sup> The I<sup>2</sup> statistic is used to describe the percentage of variation across studies that is due to heterogeneity as opposed to chance (31). The I<sup>2</sup> statistic helps researchers to assess the impact of heterogeneity on the analysis. The higher the I<sup>2</sup> statistic, the greater the amount of heterogeneity (32).

## **Patient Knowledge**

A key outcome of interest for this report was the impact of Patient Decision Aids on pregnant patients' knowledge of different obstetrics-related topics. Knowledge, in this context, refers to the participant's understanding of the specific topic addressed in the PDA—in this case, the pregnancy scenario of interest. Researchers tested knowledge using general knowledge tests about the topic of the PDA. Usually these tests used true/false and multiple-choice questions and were either only a single post-test or, less often, a pre- and post-test. All of the evidence indicated that knowledge acquisition is consistently improved when healthcare providers (HCPs) use Patient Decision Aids to help explain care options to pregnant patients.

The body of evidence for this outcome was very strong, comprising of four systematic reviews of high quality (2,9,16,18) and six of moderate quality (4,8,12,17,26,27). The improvement in knowledge scores was found across all pregnancy scenarios and most PDA formats, including:

- audio (4,18),
- computer-based (2,4,9,17,18),
- paper-based (2,4,9,17,26), and
- video (2,17,18).

However, we found mixed results for counselling formats (2,4,9,17,18). Recent primary research not included in the systematic reviews also showed mixed results overall for the effect of Patient Decision Aids on pregnant people's knowledge (19,20,22,23).

See Table 4 below for an outline of the research that found an effect on patient knowledge and the research that did not.

#### Pregnancy Scenario and Patient Knowledge

Pregnancy scenarios refer to the kinds of instances in which people have to make decisions about their healthcare in pregnancy. All of the reviews that reported on a given pregnancy scenario showed a link between a health professional using a PDA and an increase in patient knowledge. The scenarios that were examined included:

- managing breech presentation (4,9,26),
- mode of delivery after a previous Caesarean Section (4,9,12,16),
- pain relief during childbirth (4,9,26),
- pregnancy termination method (9), and
- prenatal screening (2,4,9,12,17,18,26,27).

The researchers did not look at differences in the effect on patient knowledge between these different scenarios (i.e., one given scenario was not compared against another scenario).

Recent primary studies that explored the effect of Patient Decision Aids on patient knowledge about vaginal birth after a Caesarean Section (VBAC) found mixed evidence. One study reported that knowledge significantly improved (22), another study reported no improvement in knowledge (20), while a third study reported improvement that did not reach statistical significance (19).

#### PDA Format and Patient Knowledge

As noted previously, PDA format refers to the medium in which the PDA is delivered. While systematic reviewers consistently noted that, overall, Patient Decision Aids improved a patient's knowledge (2,4,8,9,16–18,26,27), when the Patient Decision Aids were analyzed in terms of the formats of transmission, there was more ambiguity in the results. The formats that were consistently effective were:

- computer-based (2,4,9,17,18),
- audio (4,18),
- video (2,17,18), and
- paper-based (2,4,9,17,26).

In contrast, we found mixed results for the impact of counselling on patient knowledge (2,4,9,17,18).

Systematic	PDA Formats and their effect on Patient Knowledge				
Reviews ↓	Computer- based	Audio	Video	Counselling	Paper-based
High Quality Van Agt (18)	Effect	Effect	Effect	Effect	n/a
High Quality Vlemmix (9)	Effect	n/a	n/a	No effect	Effect
High Quality Yu (2)	Effect	n/a	Effect	No effect	Effect (leaflets) No effect (booklets)
Moderate Quality Dugas (4)	Effect	Effect	n/a	No effect (individual) Effect (group)	Effect
Moderate Quality Zibellini (26)	Effect	n/a	n/a	n/a	Effect
Moderate Quality Skjoth (17)	Effect	n/a	Effect	No effect	Effect
		Good-Qua	ality Primary Re	esearch Articles	
Primary Studies↓	Computer- based	Audio	Video	Counselling	Paper-based
Kuppermann (20)	Effect	n/a	n/a	n/a	n/a
Guillen (22)	n/a	n/a	n/a	Effect	n/a
Chen (19)	n/a	n/a	n/a	n/a	No effect (but improvement)
Shishido (23)	n/a	n/a	n/a	n/a	Effect

Table 4: Effects of PDA Formats on Patient Knowledge

Four systematic reviews, two of high-quality (2,9) and two of moderate quality (4,17), reported no effect on knowledge when the PDA was delivered as counselling. However, one of these moderate quality reviews reported that *individual* counselling had no effect on knowledge, while *group counselling* did demonstrate an improvement in knowledge scores (4). A high-quality review by Van Agt and colleagues (18) reported counselling Patient Decision Aids contributed to a significant improvement in knowledge. These very mixed findings, especially among high-quality studies, do not allow us to make a firm conclusion about the effect of counselling on knowledge scores.

Paper-based formats effectively increased knowledge across five systematic reviews (2,4,9,17,26). The definition of paper-based formats was sometimes ambiguous, however. Paper-based Patient Decision Aids referred to either booklets or leaflets, but some systematic reviews did not indicate which were being used. While Yu and colleagues (2) found that leaflets were effective at increasing knowledge and that booklets were not effective at increasing knowledge, the remaining systematic reviews all found significant improvements from paper-based Patient Decision Aids.

Computer-based Patient Decision Aids (including interactive digital tools) improved knowledge scores across three high-quality systematic reviews (2,9,18) and two moderate-quality systematic reviews (4,17). Audio Patient Decision Aids (one high-quality systematic review (18); one moderate-quality systematic review (17)) and video Patient Decision Aids (two high-quality systematic reviews (2,18); one moderate-quality systematic review (17)) also consistently improved knowledge scores. Given this evidence, it is likely that computer-based, audio, and video Patient Decision Aids improve knowledge.

One primary study did not support the consistent finding among the systematic reviews that computerbased interactive Patient Decision Aids were effective in improving knowledge (20). Only one primary study examined counselling as a PDA (22) and reported a significant improvement in knowledge. Lastly, two other primary studies examined paper-based formats. One reported a significant improvement in knowledge (23), while the other reported improvement, but no effect (19).

### Key Message #1

Overall, research evidence indicates that patient knowledge acquisition is consistently improved when healthcare providers use Patient Decision Aids (PDA) to help explain care options to pregnant patients. However, there is variability in the reported effectiveness of different PDA formats and their use in different pregnancy scenarios. The most consistent findings support paper-



based, computer-based, audio, and video PDAs to improve patient knowledge; whereas firm conclusions cannot be drawn about the effectiveness of counselling PDAs on improved patient knowledge outcomes. Mixed findings and a lack of comparison among different pregnancy scenarios make it difficult to draw any firm conclusions as to whether PDAs work more effectively for some decision-making scenarios than they do for others.

## **Decisional Conflict**

The literature defines decisional conflict as a state of uncertainty about the preferred course of action, most prevalent regarding choices involving outcomes that are risky or uncertain, that have the potential for high stakes gains and/or losses, and that may create feelings of anticipation of regret over rejected options (2–4). Decisional conflict is generally measured using a tool called the Decisional Conflict Scale (2–4).

Our analysis found strong evidence that Patient Decision Aid use among pregnant patients reduces decisional conflict compared to usual care. Of the systematic reviews we reviewed, three high-quality reviews (2,9,16) and five moderate-quality reviews (4,8,12,25,27) measured the effect of Patient

Decision Aids on decisional conflict among pregnant people, with all reporting that the use of Patient Decision Aids significantly reduced decisional conflict. Decisional conflict was reduced within all pregnancy scenarios that Patient Decision Aids were tested in, with choices about the mode of delivery (especially vaginal birth after a previous caesarean-section) having the strongest evidence base. Differences among the PDA formats made it challenging to draw firm conclusions about their relative effectiveness on this outcome. The three systematic reviews that examined computer-based decision

Given that the current research finds Patient Decision Aids to be useful at easing decisional conflict in several different pregnancy scenarios, we might reasonably assume that PDAs are effective in reducing decisional conflict overall, regardless of the context. Since PDAs are often designed to cater to a specific population, as well as the decision-making scenario of interest, changing the decision-making scenario should not affect the overall effectiveness of the PDA (nor should changing the population), as long as the PDA retains the core elements of providing knowledge, clarifying values, and encouraging shared-decisionmaking.

aids showed consistent decreases in decisional conflict (2,4,9). However, other PDA formats, such as booklets (2,9) and counseling (2,4,9), had mixed results in lowering decisional conflict. The recent primary research we reviewed reported mixed results compared to the significant findings within the systematic reviews.

#### Pregnancy Scenarios and Decisional Conflict

Decisional conflict was reduced when pregnant people used Patient Decision Aids, regardless of the specific pregnancyscenario in question. The decision-making scenarios studied in the literature included a variety of typical obstetrical decisions, all of which supported Patient Decision Aids to reduce situation conflict, including for: decisions about mode of delivery with a focus on vaginal birth after Caesarean Section which was examined in two high-quality reviews (9,16) and two moderate-quality reviews (12,25); and decisions about prenatal screening which was examined in one high-quality review (2) and one moderate-quality review (27).

While the review evidence supports that Patient Decision Aids are effective in reducing decisional conflict in a variety of pregnancy scenarios, the evidence is less clear about which scenarios show the use of PDAs to be most effective. Given that the current research finds PDAs to be useful at easing decisional conflict in several different pregnancy scenarios, we might reasonably assume that PDAs are effective in reducing decisional conflict overall, regardless of the context. Since PDAs are often designed to cater to a specific population of interest as well as the decision-making scenario of interest, changing the decision-making scenario should not affect the overall effectiveness of the PDA (nor should

changing the population), as long as the PDA retains the core elements of providing knowledge, clarifying values, and encouraging shared-decision-making.

The results of more recent primary research on the effect of PDAs on decisional conflict were less consistent than the findings among the systematic review evidence. Five primary research studies examined the effect of PDAs on decisional conflict with four of them looking at decisions about mode of delivery after having had a Caesarean Section (19–22). Two studies reported no effect on decisional

conflict (however, the DC scores of the intervention groups were low relative to scores that would be deemed clinically concerning) (20,22), and two studies reporting an effect (19,21). The fifth study examined the effect of PDAs when making decisions about using labour analgesia during childbirth and reported a significant reduction in decisional conflict (23).

#### PDA Format and Decisional Conflict

Computer-based PDAs showed the strongest and most consistent impact on reducing decisional conflict among the studied PDA formats, with three systematic reviews reporting this finding (two of high quality (2,9) and one of moderate quality (4). Findings for other PDA formats, however, were not consistent. Specifically, one review reported no effect on decisional conflict when booklets were used (2) whereas another review reported that booklets significantly reduced decisional conflict (9). Similarly, two systematic reviews (2,9) reported a reduction in decisional conflict from a counselling PDA, but a third review reported that counselling had no effect on decisional conflict (4).

The more recent primary research conflicted with the systematic reviews in their examination of computer-based PDAs. For example, one study examined computer-based PDAs and reported no significant changes in decisional conflict scores (20). Consistent with systematic review literature, the more recent primary study that tested counselling and paper-based PDAs found conflicting results. For example, among two studies examining counselling PDAs, one reported a significant reduction in decisional conflict (21) while another reported no difference (22). Between two studies that examined paper-based PDAs, one reported a significant reduction in decisional conflict (23), whereas the other reported no difference (19).

### Key Message #2

Our analysis found strong evidence that Patient Decision Aid use among pregnant patients reduces decisional conflict compared to usual care, regardless of the scenario in question. However, the literature was inconsistent about the effectiveness of particular PDA formats in assessing this outcome, nor could it state definitively whether certain scenarios were more conducive than others when it comes to reducing decisional conflict with the use of Patient Decision Aids.

### **Patient Anxiety**

A number of researchers examined anxiety as an adverse health outcome as the result of concerns that Patient Decision Aids may provide too much information that can overwhelm patients and increase their anxiety (9). Anxiety is characterized by feelings of worry, nervousness, or unease, and can often emerge when people are making difficult decisions about a pregnancy. In our analysis of the systematic review evidence, we found very weak evidence indicating that PDAs reduced anxiety in pregnant patients. However, we note that the main concern for healthcare providers in providing a PDA is to ensure that the PDA will not *increase* a patient's anxiety – that patients are not overwhelmed by the information provided in the PDA process. Therefore, evidence that suggests that a PDA does not increase anxiety is an important finding. In total, seven systematic reviews measured anxiety as an outcome within several different pregnancy scenarios and differing PDA-formats used (2,4,8,9,12,26,27).

Overall, there is little evidence to suggest that Patient Decision Aids reduce anxiety; however, this finding may be dependent on the pregnancy scenario and, to a lesser extent, on the PDA format being used.

The pregnancy scenarios in which the PDAs seemed to reduce anxiety included breech management, pain relief in childbirth, and vaginal birth after a Caesarean Section. Anxiety was not affected when making decisions about prenatal testing.

The PDA formats that seem to be most effective in reducing anxiety include computer-based information tools and structured counselling. Anxiety was not affected when PDAs were delivered in a paper-based format. It is difficult to pinpoint how exactly the pregnancy scenario and PDA format interact to reduce anxiety most effectively. The majority of systematic reviews measured anxiety using Spielberger's State-Trait Anxiety Inventory, a valid and reliable measure of anxiety (2,4,8,9). Overall, there is little evidence to suggest that Patient Decision Aids reduce anxiety; however, this finding may be dependent on the pregnancy scenario and, to a lesser extent, the PDA format being used.

The pregnancy scenarios in which the PDAs seemed to reduce anxiety included breech management, pain relief in childbirth, and vaginal birth after a Caesarean Section (4,8,9,12,26). Anxiety was not affected when making decisions about prenatal testing (2,4,8,9,12,26,27).

The PDA formats that seem to be most effective in reducing anxiety include computer-based information tools and structured counselling (2,4,8,9,27). Anxiety was not affected when PDAs were delivered in a paper-based format (2,4,8,9,12,26,27). It is difficult to pinpoint how exactly the pregnancy scenario and PDA format interact to reduce anxiety most effectively.

We examine the findings for pregnancy scenarios and anxiety and PDA format and anxiety in more detail in the sections below; however, readers should interpret these findings with caution given that we have assessed this evidence as being weak. As a result, we cannot say for certain if PDAs are effective at reducing anxiety in pregnant patients. It should be restated that the main purpose of

measuring anxiety within the context of PDA usage is to ensure that a patient's anxiety does not increase. This lack of an increase in anxiety is the key factor when determining the usefulness and applicability of PDAs on measures of anxiety.

#### Pregnancy Scenarios and Patient Anxiety

Through our review of studies, we found that patient anxiety when using PDAs differed greatly depending on the scenario in which decisions are being made (Please see table 5). The studies examined various scenarios where pregnant people may be offered a PDA including:

- management of breech presentation (4,8,9,26),
- mode of delivery after a previous Caesarean Section (4,8,9,12),
- pain relief during childbirth (9,26), and
- prenatal screening (2,4,8,9,12,26,27).

Two of the highest quality systematic reviews differed in their findings about the effect of PDAs on anxiety with one reporting that PDAs did not affect pregnant people's anxiety (2), and the other indicating that PDAs significantly reduced anxiety (9). The evidence suggests that PDAs do not affect pregnant people's anxiety levels when they are making decisions about prenatal screening but may reduce anxiety in other pregnancy scenarios, including management of breech presentation, mode of delivery after a previous Caesarean Section, and pain relief during childbirth (as seen in Table 5 below)

Pregnancy Scenarios in which Patient Decision Aids are Used	# of Systematic reviews that examined the pregnancy scenario	# of Systematic reviews that found a significant reduction in anxiety	# of Systematic reviews that found no effect
Prenatal Screening (2,4,8,9,12,26,27)	7	2	5
Management of breech presentation (4,8,9,26)	4	2	2
Pain relief during childbirth (9,26)	2	1	1
Vaginal birth after a previous Caesarean Section (4,8,9,12)	4	2	2

Table 5: Effects of PDA on Patient Anxiety, categorized by Pregnancy Scenario

Consistent with the previous findings, the remaining moderate-quality systematic reviews found mixed results when examining the effect of PDAs on the anxiety levels of pregnant patients within different pregnancy scenarios. It is more likely that PDAs do not affect anxiety in decision-making about prenatal screening but do reduce anxiety in other pregnancy scenarios. For example, Dugas and colleagues (4) focused on PDA formats and found that anxiety was significantly reduced in all except for one study that focused on prenatal screening. Other pregnancy scenarios looked at in Dugas's review include vaginal birth after a Caesarean Section and breech presentation, further suggesting that PDAs significantly reduce anxiety in other pregnancy scenarios.

#### PDA Format and Patient Anxiety

Researchers found that anxiety was more likely to decrease when PDAs were offered in computer-based and/or counselling formats (see table 6 below). The two highest quality systematic reviews tested similar PDA formats with both testing booklets, interactive computer programs, and counselling. Further, both conducted sub-group analyses to see if PDA format influenced anxiety levels (2,9). While one reviewer reported that, regardless of PDA format, anxiety levels remained unchanged (2), the other reported that, regardless of PDA format, anxiety was lowered (9). The authors reporting a significant effect found that the effect was stronger when the PDAs were in the form of structured counseling and an interactive computer program as compared against a booklet (9). Since the PDAs were similar, it seems likely that the difference in findings is related to the different pregnancy scenarios, as was demonstrated above, and not the PDA formats.

PDA Format	# of Systematic reviews that examined the PDA format	# of Systematic reviews that found a significant reduction in anxiety	# of Systematic reviews that found no effect
Booklet (sometimes with			
audio/visual info)	7	2	5
(2,4,8,9,12,26,27)			
Counselling (2,4,8,9)	4	2	2
Computer-based format (2,4,8,9,12,27)	6	2	4

Table 6: The effect of PDAs on anxiety, categorized by PDA format

The majority of the remaining moderate quality systematic reviews found that PDAs, regardless of format, did not affect anxiety among pregnant people, however, the results were not consistent across all studies.

#### Key Message #3

Our analysis found very weak and inconsistent evidence reporting on the effects of Patient Decicion Aids on reducing patient anxiety. Readers are cautioned that firm conclusions on this health outcome are not supported by evidence.



However, we wish to point out that the main outcome of concern for healthcare providers in providing a Patient Decision Aid is to ensure that the PDA will not increase a patient's anxiety – that patients are not overwhelmed by the information provided in the PDA process. Weak evidence indicates mixed results when examining the effect of Patient Decision Aids on the anxiety levels of pregnant patients within different pregnancy scenarios and PDA formats but does not report increased anxiety levels.

## **Patient Satisfaction**

The key goals of PDAs include ensuring that patients feel engaged in the decision-making process, are satisfied with their involvement in their own healthcare decisions, and are satisfied with associated outcomes. Moreover, past research strongly supports the principle that pregnant patients want to be involved in decision-making processes related to their care (33,34). It is therefore important for researchers to measure the level of patient satisfaction associated with using PDAs. Not surprisingly, this outcome was measured among several studies included in this report, but with very mixed results.

Six systematic reviews measured satisfaction as an outcome, the results of which will be discussed below in order of methodological quality (2,8,9,12,16,26).

Patient satisfaction was measured using either the Satisfaction with Decision Scale, or custom-made scales (2,8,9,12,16,26). An analysis of the systematic reviews indicated that, overall, PDAs did not significantly affect patient satisfaction. However, we found that the overall body of evidence for satisfaction measures was very weak as the result of disagreement among the high-quality and moderate-quality systematic reviews.

The evidence for the measurement of patient satisfaction has several limitations. Put simply, satisfaction was not measured in a sufficient number of articles and when it was, the measurement tools used were not consistent. Vlemmix (9) suggests that the lack of a firm finding for this outcome may be related to measurement insensitivity— because satisfaction is already high, it may be difficult to detect differences between the intervention and control groups. Additionally, most tools used to evaluate satisfaction are bespoke scales, which result in a lack of consistency/comparability in the findings (9).

Three of the highest quality systematic reviews differed in their findings about patient satisfaction. Two reported that PDAs did not affect satisfaction, while the third indicated that PDAs increased patient satisfaction. The two systematic reviews that reported no effect examined pregnant people deciding about delivery options after having had a Caesarean Section with one also including other pregnancy scenarios, specifically, decisions about labour analgesia and prenatal testing (9,16). In contrast, the one review that reported a significant effect only examined decision-making about prenatal testing (2). The conflicting results may therefore be attributed to the different pregnancy scenarios studied, with PDAs perhaps more related to satisfaction when making decisions about prenatal testing, but having little impact on satisfaction with decisions about mode of delivery after a previous Caesarean Section. Overall, however, it is difficult to even determine which pregnancy scenario results in higher satisfaction when the body of evidence is both limited and weak. All three of the high quality systematic reviews noted above involved written PDAs (e.g., booklets) and computer-based information (e.g., interactive computer programs) and did not differentiate in terms of the formats when measuring satisfaction making it impossible to determine whether PDA format has an impact on the level of patient satisfaction.

As was the case for the high-quality systematic reviews, results in the three moderate-quality systematic reviews varied widely and were inconclusive (8,12,26). These three systematic reviews provided very little evidence to support their conclusions and it is therefore unclear whether they can state anything at all as to whether PDAs affect patient satisfaction. More recently, three primary research articles also examined the effect of PDAs on patient satisfaction levels with the decision-making process in pregnancy. The findings were, once again, mixed. Two of the studies examined pregnant patients who had had a previous Caesarean Section and were making decisions about the mode of birth (19,20). Consistent with the systematic reviews mentioned above, satisfaction for these patients was not affected by the use of a PDA. In contrast, the remaining primary research article reported that PDAs significantly increased patient satisfaction when making decisions about using labour analgesia during birth (23). Once again, however, this finding should be interpreted with caution because satisfaction was significantly higher in the intervention group compared to the control group before the PDA was administered. If the groups differed so significantly before the intervention was even given, differences in satisfaction may not be attributed to the use of the PDA.

### **Key Message #4**

An analysis of the evidence indicated that, overall, Patient Decision Aids did not significantly affect patient satisfaction. However, decision makers should note that the overall body of evidence for patient satisfaction measures was highly inconsistent and very weak, marked by considerable heterogeneity in terms of both the measurement tools used and the scenarios and formats examined in the included studies.



### **Informed Decision Making**

Informed choice is a choice that is based on relevant, evidence-based information, and reflects the decision maker's preference and values (9,35). While knowledge is a key component of informed choice, the terms are not interchangeable because informed choice must also factor in a decision maker's preferences and values. Some methods used for measuring informed choice in the literature were questionnaires or a multidimensional informed choice measure based on the following three dimensions of informed decision making (35): knowledge about the decision-making scenario, attitude towards the scenario, and intention to participate or not to participate in the scenario.

We found a strong body of evidence from two high-quality systematic reviews (2,9) and one moderatequality review (12) indicating that PDAs increased pregnant patients' perception of making an informed decision about prenatal screening (2,9,12), breech management (9), and pain relief in childbirth (9) which suggests that PDAs can be an effective way to help support informed patient decision making during pregnancy.

It is notable that two of the three systematic reviews (one of high quality (2) and one of moderate quality (12)) specifically assessed decision making for prenatal screening only. All three systematic reviews included measures for informed decision making in prenatal screening and all three reported that PDAs significantly increased pregnant people's perception of having made an informed choice (2,9,12). Some PDA formats that were examined for use in decisions about prenatal testing include:

- structured counseling/decision analysis consultation,
- Interactive multimedia decision aid,
- video,
- booklets, and/or audio-CDs, and/or worksheet

In addition to prenatal screening, Vlemmix and colleagues' high-quality review also looked at how PDAs affected informed decision making in two other scenarios: breech presentation and pain relief in labour (9). They found that PDAs also increased patient perception of having made an informed decision in these additional pregnancy scenarios. Additionally, the PDAs that were used followed similar formats. While there were no PDA formats that stood out in the literature as being especially effective, we found more conclusive research findings for the pregnancy scenario of prenatal testing. Therefore, we can say with more confidence that PDAs are effective for pregnant patients deciding whether or not to participate in prenatal testing, but that the evidence suggests that PDAs can also help provide a sense of informed decision-making about breech presentation and pain relief in labour.

### Key Message #5

Informed decision making is based on a patient having relevant, evidence-based information, and on the ability to come to a decision that also reflects the patient's preferences and values. A strong body of evidence indicates that Patient Decision Aids increase pregnant patients' perception of making an informed decision related to prenatal screening. A smaller body of evidence indicates a similar perception of informed decisions about breech presentation and pain relief in labour.



## The Newfoundland & Labrador Context



Throughout the course of this project, the Project Team has tried to identify contextual factors that are unique to Newfoundland & Labrador and that may influence the relevance and applicability of the research-based evidence to our province and its population. This section of the report addresses these contextual factors and is based primarily on consultations with local decision makers, administrators, clinicians and stakeholder groups in the province.

Researchers at NLCAHR recognize the importance of considering Indigenous contexts in health and healthcare in Newfoundland & Labrador and encourage our health system partners to work with Indigenous Peoples to develop engagement and implementation plans that will support the co-design of programs and services that are culturally safe, accessible, and appropriate for Indigenous Peoples. We also recognize the wealth of diversity that exists within and among Indigenous Peoples in this province and urge decision makers to consider multiple Indigenous contexts in the design of new interventions in an effort to honour the full spectrum of traditional Indigenous knowledge and practices, to provide healthcare in safe and accessible ways for all, and to create opportunities for knowledge co-production and sharing. We further acknowledge that our own scope of research in this report is limited to synthesizing published research evidence and to conducting a limited number of interviews in an effort to uncover the contextual factors that may need to be considered when applying evidence in this province. We would expect that more intensive consultations with Indigenous partners would be required in implementing any findings from this research report that may have an impact Indigenous Peoples and their health and healthcare.

## **Contextualization Approach**

By 'contextual factors' we refer to local conditions, capacities and circumstances that can have an impact on the reported effects of the research evidence included in this report—such factors have the potential to enhance or to reduce the likely effectiveness, feasibility or acceptability of an intervention when used in Newfoundland & Labrador (NL). Our CHRSP Project Team helped us recruit key contextual advisors from across the province and the factors that we considered are outlined in this section, categorically. CHRSP staff spoke with, and requested information from, project team members, physicians, patients and caregivers, healthcare instructors, midwives, obstetrics managers, and other key informants to identify contextual factors relevant to this project. Interviews were confidential and anonymous. This section of the report outlines the contextual factors that we considered, and the issues that were raised in our discussions with contextual advisors.

Overall, our consultants agreed that Patient Decision Aids could be a useful means to increase a pregnant patient's knowledge about obstetrics-related topics and could also be used to decrease patient uncertainty (i.e., decisional conflict) when making decisions. While a few consultants were rather surprised about the inconclusive synthesis results pertaining to outcomes of anxiety and satisfaction, most felt that the use of PDAs would produce positive effects among pregnant patients in NL.

One important scenario to consider when implementing Patient Decision Aids in the province is the situation in which a patient's decision comes into conflict with usual clinical recommendations or is

requesting interventions that are beyond the healthcare provider's capacity and/or willingness to provide. Throughout the contextualization interviews, the CHRSP researchers highlighted examples within the NL health system in which these scenarios are more likely to arise, such as geographical areas where it may be difficult to access services. As well, the contextualization process highlighted facilitators and inhibitors to the implementation of Patient Decision Aids which are summarized below. Our consultants identified the following key contextual factors for decision makers to consider:

- the need for more obstetric services/ service options in rural and remote communities in Newfoundland & Labrador;
- the need to challenge a paternalistic culture of care provision for obstetrics patients;
- the need to promote shared decision making among patients and providers more generally in the NL health system;
- the need to address the issue of overworked healthcare staff and high staff turnover;
- the suggestion that midwives in NL can facilitate Patient Decision Aids;
- the need for health providers to accept Patient Decision Aids as important tools to help patients and clinicians engage in critical discussions about patient care, particularly given the high number of patients in NL who are asked to relocate for delivery as the result of being deemed to be high-risk cases.

Importantly, several consultants indicated that Patient Decision Aids would provide a welcome way for healthcare providers to feel more confident when engaging in discussions about available care choices and to help them ensure that their patients thoroughly understand the associated risks and benefits of their available care options.

In the contextualization report below, we provide more detail about the potential barriers and facilitators to implementing PDAs in this province. The information is categorized according to the themes that arose when we asked our consultants to tell us about contextualization factors.

## **Patient-Client Factors in NL**

## **Geography and Patient Decision Aids**

A PDA is meant to be implemented by a provider, in the context of shared decision-making, to explore a patient's options and incorporate a patient's values and beliefs (4). However, NL's geography greatly limits the options that are available to obstetrics patients. Newfoundland & Labrador has a small population that is widely dispersed among many rural/remote communities. The population is further isolated by large distances between communities, with some being difficult to access via any means of transportation (e.g., fly-in/fly-out coastal communities). This geographical reality creates challenges in the availability of services and often means patient care is inconsistent. PDAs were seen as a way to provide a more consistent care approach and format for healthcare providers engaging with their patients. The geography of this province also means that much of the NL population must travel for healthcare. While CHRSP researchers found no systematic review literature on PDAs that focus specifically on decisions related to travel and/or location of delivery, a Patient Decision Aid that would include information about the mode and timing of travel was thought to be an especially beneficial approach to address this common decision-making scenario in Newfoundland & Labrador.

Below we will discuss the challenges that Newfoundland & Labrador's geography poses in terms of available options for the location of birth and the availability of other obstetrics services. We will also discuss how NL might benefit from a Patient Decision Aid that would be related to travel and/or location of delivery.

The well-known difficulties in Newfoundland & Labrador in terms of access to a consistent primary care provider may also impede the ability to establish trusting relationships between providers and their patients who are facing tough obstetrical decisions. Our consultants remarked that many clients receive obstetrical care from whichever healthcare provider is available, which may not always be the same person. Some consultants felt that Patient Decision Aids could help this issue by ensuring all necessary information is provided to the pregnant patient in a consistent format, regardless of who is providing their care.

#### Availability of Services

A lack of choice related to the availability of obstetrics services in Newfoundland & Labrador can hinder decision making in pregnancy, and thus the effectiveness of Patient Decision Aids.

The well-known difficulties in Newfoundland & Labrador in terms of access to a consistent primary care provider may also impede the ability to establish trusting relationships between providers and their patients who are facing tough obstetrical decisions. Our consultants remarked that many clients receive obstetrical care from whichever healthcare provider is available, which may not always be the same person. Some consultants felt that Patient Decision Aids could help this issue by ensuring all necessary information is provided to the pregnant patient in a consistent format, regardless of who is providing their care.

Newfoundland & Labrador's vast geographical landscape means that healthcare services are often sparsely distributed throughout the province in an effort to accommodate the care of all communities. As a result, access to these services varies widely across the province. Our consultants commented on the disparity in obstetrics services across the four regional health authorities. Currently, Newfoundland & Labrador has ten birthing sites throughout its four Regional Health Authorities:

- two in Central Health,
- four in Eastern Health,
- three in Labrador-Grenfell Health, and
- one in Western Health.

Nine of these sites provide primary obstetrics services, while one site, within Eastern Health, provides both primary and tertiary care services. The number of births per region varies. For example, the number of births that occurred in 2020 ranged from a high of 2,263 in the Eastern Health region (which is also the most populous health region) to 333 in the Labrador-Grenfell Health region. Table 7 below provides more detail on the number of births in the province, by region.

		REGIONAL HEALTH AUTHORITY $\checkmark$					
OBSTETRIC DELIVERY SITE↓		Central Health	Eastern Health	Western Health	Labrador -Grenfell Health	Out of Province	TOTAL at each site
	Gander	206	<5	<5	<5	0	209
Central	Grand Falls - Windsor	282	5	<5	0	<5	290
Eastern	Burin	<5	78	0	0	0	79
	Carbonear	0	161	<5	0	0	162
	Clarenville	<5	100	0	<5	<5	104
	St. John's	24	1915	11	55	16	2021
Western	Corner Brook	25	<5	385	7	<5	421
Labrador	Happy Valley – Goose Bay	0	0	0	164	0	164
-Grenfell	Labrador City	0	0	0	74	<5	75
	St. Anthony	<5	<5	<5	31	5	39
TOTAL BIRTHS IN EACH REGIONAL HEALTH AUTHORITY		541	2263	401	333	27	3565

Table 7: Number of Births Reported by Regional Health Authority and Obstetrics Delivery Sites in the year 2020

Source: Perinatal Program Newfoundland & Labrador, Eastern Health, retrieved March 2022 (13).

Our consultants noted that the differences in levels and availability of staffing can be factors that contribute to the disparity of access to services. For example, according to our contextualization consultants only two sites in NL (one located in Eastern Health and one in Western) have access to an anesthesiologist 24 hours a day, seven days a week, while the other eight sites either have anesthesiologists available on weekdays from nine-to-five, or not at all. In some rural/remote communities, there can be high rates of staff turnover. These differences in available options may limit the effectiveness of PDAs and will need to be considered in their development.

Another factor that adds to the disparity in access to obstetrics services is the level of services that a birthing site can safely offer. For example, some birthing sites are not equipped to conduct Caesarean Sections, forcing those who require this service to relocate to a facility that is equipped to perform them. In fact, most high-risk pregnancies are relocated to the tertiary care site in Eastern Health to ensure a safe delivery.

#### Travel

The literature we reviewed did not focus on travel or location of delivery when it comes to common decision-making scenarios for PDAs. However, our contextual consultants highlighted the importance of including decision-making scenarios around travel for pregnancy care in the creation of any future obstetrics PDAs for the province. As stated previously, NL's vast geography and dispersed population often necessitate considerable travel for obstetrics services and delivery. The Newfoundland and Labrador Statistics Agency defines 'rural' as being any community outside the Census Metropolitan area, the four Census Agglomerations, or that has a population over 5000, a definition which indicates about 39% of NL's population would be considered rural (36). If we consider the number of people that reside

outside of a community/city with an obstetric delivery site (see Table 7), this means that approximately 44% of the population will likely have to relocate to deliver. This makes the location of delivery, and travel for care in general, a key decision-making scenario for pregnant persons in NL and therefore should be considered in the development of PDAs for the province. While travel is often necessary to receive care in the appropriate location, the mode and timing of travel are important decisions.

According to our contextual advisors, pregnant persons are required to travel to their nearest birthing facility for labour and delivery, and often for their prenatal care as well. If there are complications, they have to relocate to the tertiary care facility in Eastern Health. Some communities are only accessible by flight, therefore, pregnant persons must travel to a place with a birthing facility a few weeks prior to their due date to ensure they arrive safely, as emergency travel often faces delays. In addition to the stress related to pregnancy, pregnant people who have to travel endure extra stressors, which include, but are not limited to:

- emotional and physical exhaustion from travelling;
- lack of support from family and friends in the community to which they are relocated;
- lack of child care options at home, which may lead to delayed transport or early discharge to return home;
- financial costs associated with travel (e.g., requirement of a vehicle, gasoline, accommodations, etc.);
- risk of preterm delivery in a community without a birthing facility, or during transport;
- potential delays in receiving emergency transport;
- weather conditions; and
- loss of cultural experiences tied to births in communities with family and friends.

While the mode and timing of travel can sometimes be a shared decision between the patient and HCP, travel is often a necessary mechanism to receiving care in the most appropriate location. Therefore, PDAs are not likely to aid in decisions regarding whether or not to travel since it is not always a choice. However, the stressors listed above are important to consider in the development of a PDA, as they will likely be issues that patients will highlight when engaging in shared decision-making discussions. PDAs may help facilitate these complex discussions efficiently.

### **Demographics & Patient Decision Aids**

Health conditions such as obesity, diabetes and high blood pressure are key health conditions common in the NL population that can contribute to a high-risk pregnancy (37). Data on the female population of NL indicate higher percentages of obesity, diabetes and high blood pressure compared to the Canadian average (38). For this reason, many of our consultants noted that most of the pregnant population of NL can be considered high-risk.

These common health complications within the province make the decision-making scenarios for pregnant populations in NL more complicated. The introduction of PDAs could support discussions around these scenarios. Since high-risk pregnancies are likely to require challenging decision-making, it is important that pregnant patients are fully aware and informed about the risks and benefits of all options available to them. One of our consultants indicated that they would like to use PDAs to supplement informed discussions about the more complicated decisions that may arise as the result of the conflicting views/priorities of their high-risk pregnant patients. There is always the potential for

pregnant people to make a decision that does not align with either the usual clinical risk management or the care provider's capability/willingness to provide care. When creating a PDA, especially those that target rural and remote patients, this is an important fact that must be considered.

### The Culture of Healthcare and Patient Decision Aids

Several consultants noted that they experienced or observed a paternalistic model of care rather than a patient-centered model of obstetrical care. In the context of a paternalistic model of care, it may be difficult to implement PDAs effectively since a PDA is intended to support a more patient-centered approach of shared decision-making (4). The paternalistic model of care often does not account for the patient's values or beliefs, and may be a considerable cultural barrier to implementing PDAs. In this context, paternalism can be seen as preventing important two-way discussions between pregnant patients and their HCPs. To move away from a paternalistic approach, patient-centered care is an effective way to allow for patients to have important input in their care, and considers patient preferences. According to our contextualization consultants and online documents, patient-centered care is endorsed by the NL healthcare system (5,39,40).

Other consultants noted that the paternalistic model may be difficult to change as it has been ingrained in the culture of healthcare both in and outside of this province. This notion is supported in the literature (41) which points to the fact that many patients prefer to adhere to their HCP's recommendations without asking too many questions. Notably, some consultants we interviewed agreed that it can sometimes appear as though pregnant patients in NL do not realize that they have the ability to make their own decisions about their pregnancy at all, or that they would prefer that such decisions be made for them by their HCP. This poses a challenge when implementing PDAs, the purpose of which is to establish the patient as the primary decision-maker.

### **Indigenous Healthcare and Patient Decision Aids**

Indigenous populations are at an especially high risk from the negative impacts of a paternalistic style of healthcare and from the myriad negative cultural and health impacts of colonialism. If pregnant patients from Indigenous communities in this province must travel for care outside of their home communities, which is typically the case for those who dwell in rural and remote communities, they may often feel considerable pressure to accept obstetric decisions that do not always align with their own cultures or traditions. The decision-making context can be further complicated by issues of isolation and cultural alienation. For Indigenous Peoples, birth is often connected to the kinship and traditional lands that help shape their identity, and experiences of enforced evacuation for delivery have been reported as negative because of the stress of being separated from family, culture, and community (42–45). These anxieties can be exacerbated by the history of trauma related to state control / oppression of Indigenous families in Canada. It will therefore be critically important for health system leaders, HCPs, and patients to work together to develop culturally relevant PDAs that are based on shared decisionmaking and that involve the co-creation of knowledge to ensure that any proposed interventions being designed for use among Indigenous Peoples are created by, accessible to, respectful, safe, and culturally appropriate for Indigenous patients. One such collaborative care model being explored in this province, outlined in more detail below, is a community-led partnership to support Innu Midwifery in the Sheshatshiu Innu Nation, which aims to see Innu babies delivered into Innu hands on Innu lands. Please see the section below on midwifery for more details.

## Health Human Resources Factors in NL

## **Healthcare Providers**

Our contextualization consultants identified a few human resource challenges for healthcare providers caring for pregnant patients. Although NL has more obstetricians per capita than any other province (46), providers are faced with a low volume of deliveries (see Table 7) and a widely distributed population. This situation causes difficulties for providers hoping to maintain their specialized skills.<sup>4</sup> Additionally, healthcare providers are responsible for large catchment areas, which can lead to them being overworked, as noted by our consultants.

If obstetrical Patient Decision Aids are to be implemented in the current provincial context of obstetrical health human resources, the following factors should be considered:

- any training, staffing, or organizational changes that would be required to support healthcare providers who administer PDAs;
- the potential impact of adding extra duties to already over-burdened healthcare professionals;<sup>5</sup> and
- ensuring that healthcare providers are given sufficient time required to administer PDAs consistently and with limited support.

According to our contextual advisors, another way to relieve some of these health human resources issues would be to utilize midwifery services such as those that are already available within the Central Health region to alleviate some of the pressure that falls on other care providers delivering obstetrical care in the province. Our consultants suggested that an improved awareness of midwives' roles and further support in optimizing their scope of practice, and optimizing the use of their training and skills across the province could not only alleviate pressures on obstetricians, but also give expectant families in NL greater choice and access during a stressful, but also empowering, time in their lives. Indeed, one consultant noted that when pregnant patients do not feel empowered or have negative birthing experiences, they may not be as inclined to have more children, an issue of serious concern for a province with a declining population. In the next section, we will explore how midwives can be a valuable asset in providing obstetrical care in NL and in supporting the implementation of Patient Decision Aids.

### **Midwives and Patient Decision Aids**

Midwives were mentioned by our contextual advisors as an untapped resource for our health system and a possible facilitator to implementing Patient Decision Aids in provincial obstetrical care. The consultants suggested that midwives could facilitate shared decision-making, since they practice a

<sup>&</sup>lt;sup>4</sup> Research suggests that specialized obstetrics skills are difficult to maintain when there are fewer than 1,000 annual births per hospital (47–50), and only one hospital in NL, located in St. John's, exceeds this threshold.

<sup>&</sup>lt;sup>5</sup> The subject matter expert made the CHRSP researchers aware that PDAs are often a more efficient way to make complex decisions within shared decision-making, and are less likely to lead to both non-compliance and revisiting difficult decisions. Therefore, PDAs are not as likely to worsen time constraints and over-burdened healthcare professionals.

patient-centered style of care, and they could also provide clients with increased choice in terms of obstetrics services, including location of delivery. These facilitating characteristics of midwifery target some of the barriers to implementing PDAs that our consultants had noted, specifically a lack of shared decision-making and few options available to patients, especially in rural places.

The midwifery model of care establishes the client as the primary decision-maker, empowering pregnant people to take an active role in the decision-making process. According to our consultants, however, clients in NL are often unaware of their own rights when it comes to making their own decisions and/or do not want to be responsible for making difficult decisions related to their pregnancies. In this particular cultural factor, NL seems to be different from other parts of Canada. Several consultants noted that, in their experience, pregnant clients in other provinces expressed a strong desire to be a part of the decision-making process and to make their own decisions about their healthcare.

According to our contextualization consultants, midwifery services would expand the available options in accessing prenatal and labour and delivery services for people across the province. As we mentioned previously in our report of patient-client factors, our consultants spoke about limited birth choice being available at this time, especially for those patients seeking birthing options closer to home. Currently, pregnant patients often have to travel outside their communities to the nearest birthing facility. Homebirths are almost never an option, and a person can only choose where they would like to receive services if they live equidistant to two birthing facilities (e.g., if you live in Placentia, you can choose to receive obstetrics services from the birthing facility in Carbonear or from the birthing facility in St. John's, both of which are approximately 65-75 minutes from Placentia). Those who live in rural/remote regions often have fewer options, as it is unsafe to deliver in a place that is too far from emergency services. This current lack of options may hinder the effectiveness of PDAs implemented in the province. Since midwifery can provide a greater number of options, this care practice could facilitate PDA implementation in NL.

Newfoundland & Labrador's first registered midwifery clinic opened in Central Health in Gander in early 2020 and was intended as a pilot program that would help kick-start the profession of midwifery in this province. Our consultants indicated that midwifery care has not grown provincially beyond that Gander clinic, and that the midwives who do practice currently face staffing shortages and clinical diversions. At the time of writing, provincial support for midwifery practice in the province is limited to the Central Health region. Our consultants noted that the expansion of midwifery practice centres that had been planned for other parts of the province has been delayed as the result of the pandemic. With the current lifting of COVID-19 restrictions, it is hoped that the midwifery project will continue to expand to other areas of the province and the number of midwives in NL will increase. Many consultants were enthusiastic about the benefits that midwives could provide for the health system. The Association of Midwives of Newfoundland & Labrador continues to advocate strongly for improved access to midwifery services across the province. Our consultants noted that midwives work with Patient Decision Aids with one midwife consultant noting that they incorporate PDAs into their appointments whenever appropriate.

### **Midwifery in Indigenous Contexts**

Our consultants highlighted current efforts to return traditional midwifery to Indigenous communities in the province. One project of special interest involves training and advocacy for a midwifery model within Innu First Nations with the goal of training Innu women as midwives so that future generations of

Innu babies are born into Innu hands on Innu lands (i.e. The Innu Midwifery Project). While some challenges were noted, including the need to ensure adequate resources within the community and ambulance access to remote communities, there is widespread support for this initiative, which is now underway in Sheshatshiu. The Innu Midwifery Project has the support of Labrador-Grenfell Health and has received funding from Indigenous Services Canada. Similar health initiatives within other Indigenous contexts in the province were also noted by our consultants. These include ongoing advocacy for the revitalization of traditional Inuit midwives within Nunatsiavut and traditional Mi'kmaq midwifery services. Genuine and respectful collaboration, consultation and inclusion of Indigenous leaders and governments will be crucial in any plans related to the midwifery program and in the planned creation of any new Patient Decision Aids for use among Indigenous populations in this province.

## **Political Factors in NL**

In contextualization interviews, our consultants suggested some political factors that could affect the implementation of Patient Decision Aids in the NL healthcare system. Many consultants noted that, as for any healthcare initiative, PDAs would need a champion that would advocate and lobby for their development, introduction, and use within the healthcare system. Additionally, a recent announcement from the provincial government (51) indicates that the four regional health authorities will amalgamate into a single provincial authority in the coming year. At the time of writing for this report, it remains unclear how the health authority amalgamation will affect the delivery of provincial obstetrical services but it is reasonable to assume that these changes, among other political uncertainties, may have some impact on the implementation of any new proposed healthcare interventions, including the implementation of Patient Decision Aids in obstetrical care in the province.

## **Considerations for Decision Makers**

While the research synthesized in this report has outlined the potential benefits of using Patient Decision Aids in pregnancy-related decision-making, both the evidence and our discussions with CHRSP contextualization consultants highlighted important factors that decision makers may wish to consider when implementing Patient Decision Aids in Newfoundland & Labrador, including the following:

- Overall, the research evidence supports the use of Patient Decision Aids for obstetrical decision
  making when the intervention combines reliable evidence-based information with a
  consideration of patient values and beliefs. Patient Decision Aids were found to improve patient
  knowledge and to decrease decision making uncertainty when delivered through an open
  dialogue with a trusted care provider in an effort to outline obstetrical care options for pregnant
  patients.
- Many pregnant patients in NL face difficult decisions regarding travel for obstetrical services and for childbirth. Although the available evidence on Patient Decision Aids in this report did not focus specifically on travel-related decisions, PDAs were found to be effective in several decision-making scenarios. Given that the evidence supports PDAs as a means to increase patient knowledge and to decrease patient uncertainty, decision makers in NL are encouraged to consider research and development of local Patient Decision Aids that focus on shared decision making related to travel during pregnancy, especially as such decisions may relate to the mode and timing of such travel.
- Patients in NL are seeking access to obstetrical care as close to home as possible. Pregnant patients expect access to safe and reliable services that are provided close to their families and support systems to minimize the stress and anxiety that results from long-distance travel, relocation, and separation from the family to give birth. Our synthesis findings indicated that Patient Decision Aids have no effect on either patient anxiety or on patient satisfaction measures. As such, it is unlikely that implementing Patient Decision Aids would resolve the overall problems associated with access to obstetrical care in NL beyond ensuring that the rationale for any required travel is effectively communicated to patients.
- Chronic health conditions such as obesity, diabetes, and high blood pressure are common in NL and can contribute to higher risks in pregnancy. Patient Decision Aids support discussions between healthcare providers and their patients to ensure that patients at risk are positioned to make safer, better- informed decisions. However, shared decision making always presents the possibility that a patient's decisions may go against the clinical evidence or even challenge a healthcare provider's comfort and willingness to provide care. Such scenarios will need to be considered in prospective planning about the use of Patient Decision Aids in this province.
- In pregnancy, it is crucial to establish a trusting relationship with one's healthcare provider in order to effectively navigate shared decision-making. Decision makers in this province are encouraged to look at ways to maintain continuity of care provider(s) as much as possible throughout pregnancy.
- The health system may wish to consider ways to combat the culture of paternalism in obstetrical care. Paternalism hinders the implementation of Patient Decision Aids when care providers insist on knowing what is best and resist opportunities to listen to patient perspectives.

Provincial decision makers are encouraged to explore ways to promote more patient-centered models of care that engage in shared decision-making, that incorporate patient values and beliefs, the include discussing risks and benefits with the patient, and that leave the ultimate decisional authority with the patient.

- When developing obstetrical Patient Decision Aids for use in NL, decision makers are encouraged to seek input and perspectives from front-line healthcare workers who care for pregnant persons (e.g., obstetricians, midwives, nurses, etc.), as well as speaking with patients and caregivers from both rural and urban areas of the province. Importantly, decision makers should seek to work with Indigenous peoples and their leaders on any proposed interventions designed for use in Indigenous care contexts.
- The effectiveness of Patient Decision Aids depends on care providers having ample time to discuss patient options, risks, and benefits in the care setting. Health system decision makers will need to consider issues of time management, burnout, and overwork among healthcare providers when designing and implementing Patient Decision Aids.
- Awareness of midwives in NL as a valuable healthcare resource needs to be improved. Efforts to raise this awareness and to promote midwifery practice may be beneficial to patients seeking alternative care options as well as being helpful for other healthcare providers who currently require service support. Further support for midwifery programs in the province, as well as community-tailored programs, such as the Innu Midwifery Project, may help broaden the availability of delivery choices, support shared decision-making, and provide options for home births for low-risk patients.
- To optimize the chances for successful development and implementation of Patient Decision Aids, stakeholders will be required to advocate for, and to champion the process.
- In the current fiscal environment, health system decision makers face challenges in implementing new healthcare interventions. Although this report does not include a costbenefits or cost-effectiveness analysis for Patient Decision Aids, a more thorough assessment of associated costs should be considered as part of any proposed implementation plan.

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