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# Perceptions on the Implementation of a Concussion Passport in Organized Sport

## **FINAL report**

**Prepared for Department of Canadian Heritage (PCH)**

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**Ce rapport est aussi disponible en français**

This public opinion research report presents the results of an online survey conducted by Léger Marketing Inc. on behalf of the Department of Canadian Heritage (PCH) (Sport Canada). The qualitative research study was conducted between March 7 and March 31, 2022.

Cette publication est aussi disponible en français sous le titre *Perceptions de la mise en œuvre d'un passeport pour les commotions cérébrales dans le sport organisé.*

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# Executive Summary

Léger Marketing Inc. (Léger) is pleased to present PCH (Sport Canada) with this report on findings from a qualitative research designed to learn about Perceptions on the Implementation of a Concussion Passport in Organized Sport among youth playing an organized sport, parents who have kids playing an organized sport, adults playing organized sports, and subject matter experts. This report was prepared by Léger Marketing Inc. who was contracted by PCH (Sport Canada) (contract number C1111-210393/001/CY awarded January 28, 2022).

## 1.1 Background and Objectives

For some years now, the different levels of government (federal, provincial, and territorial) have implemented a common approach to protect participants in organized sports activities from concussions and their consequences. To this end, a surveillance system to share information about the incidence and treatment of concussions has been discussed but not introduced yet. One way identified to achieve this end goal would be to establish an individual passport identifying the number, follow-ups, and context of concussions that a participant has suffered. All participants would provide this information to their clubs, associations, and sports federations at the time of registration.

Most recently, a survey conducted by PCH (Sport Canada) provided data on the idea of a concussion passport in organized sports. The majority of the survey participants said "yes" when asked if they would be willing to share their concussion medical history with coaches and sport organizations.

As stated, qualitative data was needed to gain a fuller understanding of the Canadian public's perceived value, benefits, interest, and concerns on the implementation of a concussion passport in sport. This research is also a complement and build on current concussion-related quantitative data findings from the PCH (Sport Canada) 2021 Safety, Ethics, Equity in Sport Survey. It will help guide future directions of Government of Canada support and leadership in the areas of concussion management and prevention as well as directly inform the work of the federal-provincial and territorial (F-P/T) Concussions Working Group (co-chaired by PCH Sport Canada) and the F-P/T Sport, Physical Activity and Recreation Ministers.

### Objectives

The goal of the Public Opinion Research (POR) project will be a final report (in both English and French). This report will include qualitative data findings stemming from key focus groups and subject matter experts consultations identifying the perceived value, benefits, interest, issues, concerns, barriers, and constraints of implementing a concussion passport for participants.

## 1.2 Methodology

### Qualitative Research – Focus groups

Léger conducted a series of ten online focus group sessions with French-speaking and English-speaking Canadians. Conducting the groups online offered the opportunity to regroup people from all the regions in Canada. Four focus groups were held with adults playing an organized sport, three focus groups were held with youth playing an organized sport and three focus groups were held with parents who have children playing an organized sport. Two groups were held in French, and the eight other groups were held in English. For each online focus group, ten participants were recruited by our professional recruiters. A total of 91 recruits participated in the online focus groups (see Table 3 for details). All participants in the focus groups received an honorarium of \$100.

The focus groups were conducted online using Focus Vision's CMNTY platform. This platform allowed for video conferencing groups, observers in a separate virtual room, chat between participants and the moderator, and chat between the observation room and the moderator. Each session was 90 minutes long, thereby ensuring the involvement of each participant.

All sessions allowed for remote participation.

Table 3. Details of the focus groups

Session Detail	Date	Recruits	Participants	Language
Adults – Atlantic	March 23	10	8	English
Adults – Quebec	March 23	10	9	French
Adults – British Columbia	March 24	10	9	English
Adults – Territories	March 24	10	9	English
Youth – Ontario	March 28	10	8	English
Youth – Prairies	March 28	10	9	English
Youth – British Columbia	March 29	10	10	English
Parents – Quebec	March 29	10	10	French
Parents – Ontario	March 30	10	9	English
Parents – Prairies	March 30	10	10	English

### Qualitative Research – In-depth interviews

As part of PCH (Sports Canada)'s exploration into the development of a national database to track concussions that occur in sport, in-depth interviews were also conducted with a select group of subject matter experts.

Léger was responsible for the recruitment and scheduling of the individuals for this study. The list of interviewees was provided by PCH (Sport Canada). Interviewees were contacted in advance by the Department alerting them to the pending contact by Léger and the reason for the interview. The study population was organized broadly into the following categories:

- National/Provincial/Territorial Sport Organizations
- Government Representatives
- Coaches
- Health Experts

The interviews followed a structured questionnaire that was designed by Léger using an outline provided by PCH (Sport Canada). Forty interviews were conducted by a senior Léger professional and took on average approximately 45 minutes to complete.

The interviews were conducted in the official language of the interviewees' choice (French/English).

## 1.3 Overview of the Findings

### 1.3.1 Focus groups

Focus groups were held with three specific target audiences: 1) parents of youth playing in organized sports, 2) youth and young adults playing in organized sports and 3) adults also playing in organized sports. While these three targets did show some discrepancies in terms of their interpretation of the risk of head injury or how important this issue was for the sport they play in, all three target audiences displayed a similar response to the concept of the concussion passport.

In general, participants tended to somewhat minimize the risk of head injury for their sport. Participants in all three segments did recognize the potential severity and the risk of long-term damage that could ensue from a concussion but tended to feel that the occurrence of this type of injury was fairly low. They tended to believe that the risk became more real for older athletes (late teens, collegiate, professional sports) and for elite, national level athlete competing at very the top echelons of their sport. The danger for pre-teens playing in recreational leagues was at the other far end of the spectrum.

However, the consensus was that more should be done to prevent head injury in sport and more efforts should be put in raising awareness as to the adequate treatment of the condition and how back to play protocols should be followed by parents and athletes. As well, better training for coaches, their assistants, league, and association officials were seen as necessary.

Among those who had personally suffered or parents of youth who had suffered a concussion, the recollection of the full process from the event on the field of play and the later return to play were varied. But in all of these cases, they (the athlete or the parent) made the final decision on when was the right time to go back to the sport, regardless on whether or not that decision was aligned with the recommendation from their family physician.

When presented with the general concept of the concussion passport, the pattern was the same for all three target audiences. After hearing parents or peers discuss a past event of a concussion and the trials that followed, the risk of head injury and the need for greater awareness of these risks, initial reactions to the concept were rather positive. The need to "do something about it" was apparent. However, participants soon raised concerns, and several became opponents of the idea. Generally, there were four kinds of concerns:

1. **Privacy concerns:** The possibility that individual level highly confidential medical information could be shared potentially outside the health care system was a fundamental concern. Some believe that they alone should decide if and when their personal data can be shared. Any possibility that some information could be shared with leagues, associations, coaches, or any third party raised red flags.
2. **Potential discrimination:** For athletes and parents, they feared that information regarding their concussion history could hurt their or their child's ability to "make the team". At the time of tryouts, coaches could decide to pass on a player based on the information found in the passport and opt for another player of similar potential with no concussion history. To parents and athletes, this would be a form of discrimination.

3. **The right to choose:** Both parents and athletes believe that divulging information about their health should be their decision and theirs alone. Sharing personal information should, in their view, always be voluntary and their own responsibility. The idea of the passport as presented was objectionable based on this principle.
4. **Other third parties:** Some participants also feared that access to the passport could lead to interested third parties using that information for non-intended purposes. The example of insurers was used by participants in different groups.

While only a minority still supported the idea of the passport, by the end of the sessions, this did not deter from the fact that participants felt “more should be done” to protect our youth and Canadian adults playing sports. Participants did feel that if the information about concussions were used only at an aggregate level to better understand risks, occurrence by sport, by age group and other significant variables; they would be supportive. If this type of data helped both the medical and sport communities in Canada, they would be supportive of that effort. For most, truly protecting Canadians, the first need must come from greater awareness, better communication and increased training on concussions in sport. Other suggested more voluntary systems where parents and athletes could share their concussion history when they believe it is in their best interest. Regardless of the mechanism used (e.g., medic-alert analogy or any other potential systems), the idea was always framed in the context of voluntary disclosure.

### 1.3.2 In-depth interviews

When considering the overall volume of amateur sport that occurs annually in Canada across all ages and levels, a very small percentage is subject to any organized collecting of concussion data. When data collection does occur, it tends to be among elite level teams and during major competitive events.

The collection of concussion-related data is often part of a broader program of monitoring the health and performance of athletes. The one broad-based sport organization that is closest to having an all-encompassing concussion tracking program is Rugby Canada. They are able to extract this type of information from their player registration database.

Barriers to concussion data collection include:

- Privacy concerns
- Questions around who should enter and maintain the database
- Challenges with proper diagnosis
- Technological structure of something cross-jurisdictional and cross-sport
- Cost

Privacy is of paramount concern. Concussion data is health information that needs to be managed carefully, with consideration on how it gets compiled and who has access to it. For associations and coaches, another major uncertainty related to the building and maintaining of such a database included who would be responsible for entering the data and what the platform would consist of.

In many leagues, there are a few examples of teams electronically tracking player injury information, including concussions. This tracking usually occurred through software applications provided by private companies which were maintained by a team trainer or other support staff. This type of injury tracking was usually with a higher level, elite team and there typically was a cost associated with the application.

Extending this to a system that encompassed an entire sport at all levels, let alone one that includes multiple sports is very difficult to envision. There is neither the human resource capacity nor the financial wherewithal to extend, what is done occasionally at a very high level, throughout an entire sport.

The cost of developing and maintaining a concussion database was not only a concern measured in dollars, but also in the human resources required to design and implement a system.

All stakeholders interviewed for this study spoke positively of the efforts being made currently to raise awareness of concussions in sport, better detection protocols and educating on the steps necessary to ensure it is properly treated before returning to play. There was a strong feeling these were important initiatives, and they were making a difference in how the community was approaching concussions in their sport. While supportive of a concussion database, there was a concern it may detract from these efforts.

Should a database be established, there would need to be careful thought as to what information is collected and how it is managed. While a personalized database would be beneficial in terms of mitigating multiple concussion syndrome, there is a concern the historical concussion record could be mis-used by elite athletic programs as a screening tool when recruiting participants. And even the slightest potential of this would have a detrimental impact on an athlete/parent's fulsome participation in a database.

While there are concerns and some doubt about the ability to develop and launch a multi-sport concussion tracking program, there is a very strong desire among researchers and sport associations for more accurate data on concussion incidence in sport. There is a need for more aggregated data to help further understanding about concussion in sport, and also assist in measuring the impact of changes that sports have already implemented to manage concussions.

Concussion in sport is not viewed like other injuries. For too long it was rarely recognized as a 'real' injury. This is changing with the advent of consistent awareness and detection methodologies that many sports are incorporating, such as mandatory certification requirements for teams and coaches. In addition, greater focus on ensuring a medical assessment is performed and a Return to Play is required is improving how concussions are treated. Long held views are beginning to change and will need to continue to do so to ensure concussions are consistently treated with the seriousness they deserve.

## **1.4 Notes on Interpretation of the Research Findings**


The views and observations expressed in this document do not reflect those of PCH (Sport Canada). This report was compiled by Léger based on the research conducted specifically for this project. This research is not probabilistic; the results cannot be inferred to the general population of Canada.



## 1.5 Political Neutrality Statement and Contact Information

Léger certifies that the final deliverables fully comply with the Government of Canada's political neutrality requirements outlined in the Policy on Communications and Federal Identity and the Directive on the Management of Communications.

Specifically, the deliverables do not include information on electoral voting intentions, political party preferences, standings with the electorate, or ratings of the performance of a political party or its leaders.



Signed:

Christian Bourque, Senior Researcher

Léger Marketing Inc.

# Detailed Results – Focus groups

## 2.1 Parents

### 2.1.1 Head injuries in sports

In the parents of youth practicing organized sports, the perceived risk of head injury varied according to two key factors: 1) the nature of the sport and 2) the age of their children. While hockey, soccer and football topped the list as being high risk of head injury, other parents also mentioned that people may not be aware of the risks of head injury in horse show jumping, swimming, or baseball. Among parents of older teens, head injuries were considered a major threat among other types of frequent injuries (i.e., knees, ankles, torn ACLs, shoulder separation), while parents of younger children believed the risk of head injury was rather small compared to sprains, bruises, and other mild injuries. That was also true for parents whose children are involved in sports which, in general, parents of older children had identified as higher risk earlier in the group.

Parents seemed to be divided in two camps: 1) those highly aware of the risk of head injury or concussions in the sport their children were currently practicing, and 2) parents who tended to downplay that same level of risk. Parents largely indicated they knew little if at all about the actual risk for a particular sport for a child of a specific age.

In the first group, these parents believed that the threat was real and that coaches and other officials on the field/ice or otherwise would have the necessary training and awareness of guidelines and protocols to deal with the immediate situation if their child were hurt. They generally trusted that all those involved would act to protect the health and well-being of their child, while few had mentioned that this was directly communicated to them by sports organizations or coaches. These parents “thought” this would be the case. In only a few instances did parents mention that their child’s coaches had addressed parents directly with regards to protocols in place and training they had taken to deal with this type of serious issue.

In the second group of parents, concussions are something they hear about, mostly in high level if not professional sports, but seem to feel that the likelihood of this happening to their child was low and would remain manageable as a parent. This group tended also to minimize the severity of a concussion, often using references to their own youth on the ice/field, where they had gotten “their bell rung” or “saw a few stars” but were told to get back on the ice/field. Many believed that if they had suffered a concussion, they had only felt mild symptoms if at all. Using personal experience to relate to the issue was a common occurrence.

In the same way, much of the language around the risk associated with their sport was if they had personally witnessed or seen a playmate of their children suffer from a head injury with their own eyes. Parents did not mention hearing about statistics or sheer numbers of instances where young Canadians receive a diagnosis of a concussion or miss any play due to a head injury. While parents said they know the problem exists, they seemed to downplay that risk for their own child. Other ways some parents downplayed the risk of head injury was the fact that their child was “only in recreational” hockey/soccer or any other sport, not at the “double-letters or elite level” where these things were bound to happen more often.

Several parents also indicated they had received a series of documents at the time they registered their child in a sport organization and that some of these documents were a “waiver” of some sort related to head injuries. This was particularly the case for Ontario parents. However, most indicated they had signed the documentation without paying much attention to it. It was simply one other form to sign to allow their child to play.

The only exceptions in terms of perception of risks were parents of children involved in elite/national programs or currently in American colleges on sports scholarships. At this level of elite sports, teams and coaches had fully briefed parents on concussion protocols and return to play protocols as well. Team or association physicians and physios' roles and responsibilities were specifically outlined to the young athlete and their parents. This seemed to echo some of the comments made by other parents that the risk of head injury would rise significantly depending on the age of the child and the level of play (from recreational to elite).

### **2.1.2 Concussion management**

For parents who said that their child had suffered a concussion or head injury, the nature of their experience both at the time of the event, the immediate follow-up to the event or the return to play protocol were varied. In almost all cases, parents reported that their child was immediately taken off the field of play and often taken to a dressing room or more private area to be directly assessed. When asked if these parents believed the coach or assistant who cared for their child was competent in managing firsthand a potential concussion victim, few were outright affirmative. Most believed the coach or assistant did their best in the circumstances and simply asked them to take the child to see a medical professional right away. Again, the exception were parents of children in highly competitive levels (usually older children as well) where they knew a medical professional was present on the field/ice or other venue.

Once the assessment was made that their child may be suffering from a concussion and should see a physician, all parents said they indeed followed the recommendation. When the physician had established the likelihood that the child was indeed suffering from a concussion, then the time off the field and recovery period varied greatly. For some, there were return visits to the physician to assess progress, for others simply a recommendation to stay off the field if symptoms were present. Parents believe they were adequately informed by their physician on the potential symptoms, what to do about them and how to identify when their child might be capable of returning to school and eventually play.

Very few parents said that it is a health professional who "cleared" their child to go back to play. Most said that they, as the parent, made that decision based on the advice they had received from their physician post-event. In most cases, they waited for the necessary period to elapse, while most said their child was "fine" and could go back to all their normal activities earlier than planned.

One other element which added to the complexity of concussion management was the age of the child. Into their late teens, some parents felt their child pressured them to let them go back to play and that their child believed they were the ones now making that decision. Furthermore, confidentiality issues between physician/patient and parent also played a role in the back to play decision.

Among the other parents present in the groups, the discussion surrounding concussion management seemed to generate some confusion as to what was the "right" process or protocol and how recollections from parents of children who had suffered concussions seemed to differ from what they had heard in the past. Again, this seemed to suggest fairly low awareness among parents about concussions themselves and limited knowledge on how they are identified, treated and addressed.

### 2.1.3 Concussion Passport

Reactions to the concept of a concussion passport were largely similar between all three segments which were part of the focus group exercise. In general, reception is initially positive, while opposition tended to grow as concerns, questions, and objections were voiced by participants.

For parents, the first portion of the groups' discussions ended on a general consensus (not that consensus was purposely sought by the moderators) that greater awareness, and more training was necessary so that the issue of sports-related head injuries be better addressed in the future. Parents hearing other parents recall the events surrounding the concussion suffered by their children, also created a general sense of empathy. This may have contributed to initially positive reactions to the general concept of a concussion passport. It should be noted that moderators quickly adapted to the use of the concept of a passport, as Canada was moving away from vaccine and passport mandates related to the COVID-19 pandemic. The word "passport" did draw several negative reactions from participants, namely ones from Western Canada. Once the moderators moved away from the use of the word passport, reactions tended to be positive. Parents indicated that the idea that one's concussion history would follow them from one team, club, organisation, or league to the next (i.e., from U-14 to U-15 in soccer) was deemed as an efficient way to prevent a next event or to better enable responsible adults to deal with a future event and limit the risk of that event occurring. It should be noted that, at first, most parents of children who had suffered concussions in the past were rather positive about the idea. It seemed, at first, that medical professionals would also directly benefit from the circulation of this information. Rather than solely relying on the information provided by parents or the children themselves, the flow of information coming from medical professionals would enable a faster, more appropriate response in the case of a subsequent concussion.

However, 5 different types of objections were quickly raised during the focus group sessions with parents, which were also largely echoed in the youth and adult segments. These objections were as follows:

1. "Would or could the information shared in the passport prevent or undermine the chances of my child making the team"? This remained the core concern of parents whose children were involved in any competitive sport even at the local level. The "fear" that coaches or organisations could "pass" on their child at the time of trials to limit their risk was seen as very real. As one put it: "Of course between my child with a concussion history and another child with similar talent but with a blank passport, this would mean the passport would discriminate against my child."
2. Will the information in the passport supersede the parent's prerogative on whether their child is fit to play or not, or when they should return to play? Parents fundamentally believed that the decision regarding what is right or wrong for their children is their own. The fact that other individuals may directly be involved in determining their child's future in sport was unsettling for many.
3. The issue of data privacy was also very important to parents. Given that concussion history would be shared with certain individuals, parents shared concerns over who would have access to what they consider private and highly sensitive medical information about their child and how that data would be used or shared. Some felt that certain individuals (league or association administrators or coaches) may not have the qualifications, ethical consideration or sense of responsibility to handle confidential medical information in the right way. As one put it, "word would get around that this player is a liability with having sustained 4 concussions and other parents would put pressure on the coach for their child to get more ice time given their "blank history..."

4. Other parents also wondered if the information found in the passport could affect their capacity to obtain college scholarships and if the information could be used in a scoring system of some sort where their child's future maybe negatively impacted.

5. Some parents were also against the idea that highly confidential medical information about their children may circulate or be provided to certain persons who are not medical professionals without their express consent. This was deemed an unacceptable breach of privacy.

In the parent groups, as participants almost invariably raised these concerns, initial support for the general idea became a form of opposition. When asked how or in what condition would a system allowing to better protect Canadian teens and children involved in organized sports could work? parents suggested the following:

1. With parents, the consensus was that the idea of the passport was too contentious and that the real issue lay with raising awareness on the risks of head injury among parents, coaches, officials, leagues, and associations. Prevention appeared as the primary objective of any initiative related to the safety of Canadian children. Most admitted they did not know if their child's coaches and assistants were appropriately trained on preventing head injury, on direct intervention if an injury occurred or on how to deal with a safe return to play protocol. Parents also felt they may be underestimating the risks for their own child or the potential damage concussions may cause.

2. Others who were not opposed to the general concept of a "passport" believed the sharing of information regarding the concussion history of a child be limited only to medical professionals, like any patient file would. They felt that if their child was injured on the field of play and taken to a physician, that this professional could immediately access that patient's concussion history to help provide for a "better" or "faster" diagnosis. The belief was that this ready access to the patient's concussion history would also contribute to a safer protocol when it comes to that child's return to play. Most tented to agree that the sharing of information between medical professionals was a positive step forward and still protected the privacy and confidentiality of information. These same parents felt that sharing information regarding their children's medical history to persons outside the health care system (coaches, leagues, or associations) would then be their own decision as the parent or guardian of a child.

3. Some felt the concept of the passport should be limited to elite, national level athletes and for older teens where the risk of head injury was not only higher but that the sport itself was potentially becoming a career. In these cases, the obligation to be assessed by a physician coming into this level of sport would be mandatory and that regular follow-ups would also be part of the process. But, for example, if one's child was playing recreational junior high basketball, all of this was not necessary.

## **2.2 Youth**

### **2.2.1 Head injuries in sports**

Among the youth groups, most believed there was a medium to high risk of head injury in the sports they are currently involved in, even if they felt the occurrence was fairly rare. Of course, that perceived risk was different depending on the sports they practised but several commented that people may not understand how head injuries could occur in their sport. For example, one young woman mentioned that head injuries in competitive swimming were common and mostly

happened during practice and not competitions. As swimmers share lanes, head-to-head collisions did happen and that hitting the wall was a concern in practice as swimmers could be distracted during lengthy repetitions.

It was interesting to note as well that severity of injury for young Canadians, mostly among those who were playing at a highly competitive level, tended to be associated to how long they would be kept off the field or the total recovery period, rather than the risk of permanent or long-term damage.

When asked if their coaches, assistant coaches, or league officials had briefed or trained players on the risks associated with head injury or told how coaches or officials were trained to handle them, most participants answered negatively. Rather they said that they 'assumed' people around the team or surface of play would 'know what to do'. The only exceptions were youth who said their team always had a physiotherapist on the sidelines with them. They said that the discussion around concussions in our society had changed in recent years and that they would feel comfortable talking about it with their coaches and parents.

Most said they had witnessed a teammate or opponent sustain a head injury in the past and that it could happen to them as well. As such, regardless of the level of risk they identified with their sport, the likelihood of head injury was never zero. However, regardless of the fact on whether they themselves had been a victim or not in the past, that risk was not scaring them away from practicing their favorite sport and that all said they would return to play if it happened to them. Their sport was their passion, and it was up to them to decide if and when they would quit.

Youth participants did not wish to undermine the gravity of the issue of concussions in sport and tended to feel that this sense of gravity needed to be escalated as the number of concussions for one individual increased. The discussions often gravitated around the problem of "multiple" concussions. As well, many references were made to professional sports or top elite amateur athletes when discussing the issue of concussions, while a clear distinction was made between these highly competitive environments and more recreational sports. Several young adults also mentioned dreading the decision of having to quit the sport that helped them forge their identity, notwithstanding if that decision arises from concussions, a banged-up knee that always hurts or because of family-work circumstances.

### **2.2.2 Concussion management**

Among youth participants who said they had suffered a concussion, the storytelling surrounding the event was varied. For some, they "believed" it was a concussion because they recall suffering from some of what they believed were the common symptoms, while it was not diagnosed by a medical professional (there was no consultation). For this group, the symptoms were mild enough and subsided quickly enough that it did not require medical attention. For others, they indeed consulted a medical professional at the time of the event but return to play recommendations or protocols were very different.

Among those who received a diagnosis from a medical professional that they had suffered a concussion, few divulged that information to their coaches or association or league officials. They rather said they were "not feeling well" and would miss practice or the next game. They felt it was up to them to say what they wanted or needed, and some even felt it was "better for them" not to divulge the fact they had suffered a concussion. Some did say to their coach that they were told they suffered from a concussion, but that "it was mild and they would be back on the team in a few days".

When asked if the physician consulted had established a protocol regarding return to play, most said that the physician had provided a list of recommendations regarding rest, watching for certain symptoms, when to go back to school and eventually, their sport. In most cases, a follow-up examination was not part of that protocol, and the young adult was the one who determined when they were fit to play. In several cases, young adults did not respect the time schedule established by their physician and returned to play sooner, because they “felt fine”. For different reasons, which were not overtly mentioned, they had a strong sense on the time and date and all of the decisions to be made regarding getting back to play.

This strong sense of empowerment over all decisions regarding their “passion/sport” also transpired when the concept of the concussion passport was later discussed.

### **2.2.3 Concussion Passport**

Similar to the parent focus groups, youth/young adult groups tended to respond favourably at first, before gradually changing their position as concerns were raised by fellow participants. Initial positive reactions were largely the outcome of a general consensus surrounding the importance of protecting athletes against head injuries in sports. It first appears that “any” step in that direction would be a good one.

Very quickly, some participants mentioned outright that they would personally be reluctant to share any information regarding their concussion history if they believed it may impede on their chances to play, make the team, progress or simply enjoy their passion. Some commented that they would voluntarily withhold information about their condition if they felt it may be against their stated self-interest. Furthermore, if they did suffer a concussion, they alone would determine when they could resume play and would not communicate information that may delay their return to their sport.

Direct objections to the concept of a concussion passport were as follows (beyond some negative comments about references in using the term “passport” in the context of the COVID-19 pandemic):

1. Their decision to play or not is theirs alone. Young adults believed that the concussion passport may and could be shared with individuals who could interfere with their right to play and that this decision, as a young adult was their own only.
2. Would or could the information shared in the passport prevent or undermine the chances of them “making the team” or “being a starter” as opposed to being on the bench? This was almost identical to the concern raised by parents whose children were involved in any level of competitive sport. Young adults felt that their concussion history could be used to determine if they made the team and believed that coaches or organizations would use the information to make decision that would affect their future in the sport. Again, the concept of the passport as enabling coaches or associations to “discriminate” between two players of equal talent was used.
3. The issue of data privacy was also raised by young adults. In the same way that parents had mentioned, they would be in favor of information being shared between medical professionals to help them make a better-informed diagnosis and prescribe an appropriate plan for the athlete’s return to play protocol. Youth groups believed they alone could make the decision to share any information about their concussion history OUTSIDE of the confidentiality and privacy policies in the health care sector that protects them as individuals.

4. Another concern raised by youth and later echoed in the adult groups was the concern over insurers. If the data regarding one's concussion history could be shared outside of the physician's office, could such information be used or accessed by private insurance companies and impact their access to life insurance products or the premium increase that such information-sharing could cause.

5. Most importantly, the concern is over the loss of control over their own personal information and the fact that non-medical decision-makers (i.e., coaches, leagues, universities, associations, or official bodies) could access, share and make decisions based on confidential and private information. For those young adults playing in more recreational Sunday leagues or evening adult leagues, the general sentiment is that for the leagues themselves, the concussion history of an adult player was "none of their business" ... period.

Similar to the adult sessions, youth participants, as they slowly rejected the concept of the passport, tended to switch their focus more on awareness, training and prevention. They believed that attitudes have changed regarding head injuries in sports, but that more could be done on this matter. Participants said that their coaches or associations had not shared documents or briefed them as young athletes on concussion prevention, treatment or any other aspect related to head injury. They also said they generally trusted that coaches would "know what to do" but did not know if they had received any training or information on those subjects. Among Ontario youth, the moderator asked about awareness of Rowan's Law, and only one person raised their hand but could not recall exactly what it was.

Another participant suggested that some form of national database should be gathered but only used at an aggregate level to inform the public on the risk, occurrence, and severity of concussions by sport, age groups, gender or any other variable that may help improve the situation for the future.

One participant also suggested that if the passport was to exist, that it should be on a voluntary basis only. If one athlete decided to share a number, card, barcode, or any system put in place to allow someone to access their concussion history, this was totally fine and would prove helpful. But again, the decision should be that of the individual. Another used the analogy of the medic-alert bracelet and that a coloured bracelet system could be used. If, voluntarily, an athlete wore a coloured bracelet that is known to be about concussion history, this could help that athlete in the event of a future head-related injury. Because the nature of the injury, if that athlete was confused or hurt, others could directly assess the situation based on the bracelet.

## **2.3 Adults**

### **2.3.1 Head injuries in sports**

The "adults who participate in organised sports" focus groups quickly became "hybrid" sessions, as a majority of participants were also parents of children who participate in organised sports as well. The moderator took the time to discuss both aspects, but mainly focused on them as adults. The views of these participants when they discussed their children were presented in the previous parent section.



When asking about the risk of head injury in the sports they practice as adults, most tended to downplay the likelihood of head injury while acknowledging that the risk still existed. Compared to young adults and children, most mentioned that the level of competition was rather casual and that the risk of injury-causing collisions was less frequent. Some participated in organised leagues without referees and those players adapted their level of aggressiveness accordingly. Beyond the risk associated with the sport they now played; these participants were also the ones that tended to downplay the impact of head injury in sports altogether. As one put it, "I remember getting my bell rung a couple of times when I was young but back then they would simply tell you to stop whining and get back on the ice." While participants acknowledged that greater awareness and attention needed to be paid to head injuries, they mostly framed it in the context of their children playing sports and not for themselves. Most of their comments continuously ended up being about youth and the moderator to ask them to focus on adults practising organised sports.

Once refocused, they tended to refer to more frequent injuries being about joints, "old" nagging pains from past injuries, bruises, and sprains. Head injuries were treated as exceptional events, and they did not seem to remember seeing that type of injury in their leagues or associations. They had no knowledge about how their leagues and associations handled the matter, nor did they remember if any information regarding head injuries had been conveyed to them. As one put it, "they did tell us where the defibrillators and first aid kits were but nothing on concussion. At our age, dying of a heart attack on the bench is much more likely than seeing stars on the ice."

As soon as the focus moved away from their own child to a more general discussion on concussion in sports, parents' concern on the issue tended to disappear.

### **2.3.2 Concussion management**

Some participants remembered suffering from something that they now identify as a concussion when they were younger, but "back then", they had not consulted a physician, were not given a diagnosis or recommendations about recovery and back to play protocols. Some recalled missing school, having difficulty in the light, bouts of nausea and other symptoms they associated with concussions, but believed the return to play within a few days to a week and was "fine". Only one participant recalled a sport-related concussion they sustained as an adult, resulting from a bad fall. In the case of that participant, the main preoccupation was related to missing work and the impact on family obligations. That person did consult with a physician and followed the recommendations from that medical professional. One participant was also a collegiate football coach at a university in Atlantic Canada and did explain how they now handle concussions, associated protocols and discussed certain computer software now used to track young athletes in their program. This was seen as the "right way to go" for the other adults present stated they were rather ignorant to the matter.

Again, most adults tended to refer to events or cases associated with their children and tended to 'ignore' their own reality. The general consensus was that more attention needed to be paid to head injury in light of their potential long-term consequences.

### **2.3.3 Concussion Passport**

Similarly, to parents and youth, adults were very receptive to the idea of a concussion passport at first before raising concerns later on in the session. At the same time, they always framed the discussion in terms of elite, competitive and youth sports. Getting adults to focus on Sunday leagues\adult casual leagues was rather difficult.

As adults, they did not really see the usefulness of the passport itself. One participant simply said: "As adults, we will make the right decision for ourselves, we all have to be on the job the next morning". However, they were supportive of a passport concept that would protect their children.

Concerns spontaneously raised by adults were almost identical to parents. A lot of the focus was on privacy issues, similar to what parents had mentioned. Adults believed that the passport usage should remain voluntary, while they did believe that the system put in place should be stricter for higher risk sports and should take into consideration the age of the children involved.

For adults, most believed they should be open about their injury history to allow teammates or organizers to help them if something were to go wrong. They believed that admitting a past concussion should be no different than saying one has diabetes or has a severe allergy. However, they quickly became opposed to the concept as soon as the discussion would move to their children.

## **Detailed Results – In-depth interviews**

### **3.1 Current state of Data collection of Concussion**

#### **3.1.1 Concussion Tracking in Amateur Sport**

Overall, there is very little organized, dedicated tracking of concussions that occurs in sport. Most sport organizations/officials interviewed agreed that at the provincial and territorial levels, there was some general health data collection taking place. This was in the form of athletes completing a medical history, including concussion history at the beginning of each year before play. This information is confidential and depending on accessibility can be examined to assist with injury treatment should one occur during the season. At the grassroots/youth level the typical form of data collection was a paper form that was placed in the athletes file held by the governing association.

There were some injury tracking efforts at the individual team level and a few sports identified programs that were in place at the elite level and for major competitions. The information collected was primarily to monitor performance and track progress with training, but it was also useful to register injuries, treatment, and monitor recovery.

Based on the interviews, only one sport, rugby, came the closest to having the ability to track concussions of its athletes throughout their playing career within that sport. Rugby Canada has had in place for almost a decade a national registration database for all players on teams sanctioned by the organization. Currently, the database consists of approximately 30,000 players.

Players create a profile which stays with them through their playing days and is transferred between rugby teams, so long as it is a sanctioned team under Rugby Canada. Every year, players are required to update their profile. High school and university teams are not included in the system; however, it is possible for the Rugby Canada player profile to include other sport activities he or she was participating in.

A recent international rule change introduced a 3<sup>rd</sup> card into a rugby referee's repertoire—the Blue Card. The Blue Card can be pulled against a player should the referee suspect that player has suffered a head injury that could represent as a concussion. When a player is blue carded, they must leave the field of play and be assessed by a medical professional. Following the match, the player's Rugby Canada profile is updated with the Blue Card information, and they are listed as inactive if a concussion is confirmed, which means they are not eligible to play another match. The player and the coach of the team is emailed this information along with instructions of what is required to return to eligibility.

To be listed as eligible for participation, the player's profile must be updated with a report from a medical professional clearing the individual to play.

At present, the Blue Card is used in several countries and was being piloted last year in Ontario with a plan for broader application in that province for the 2022 season. The goal is to expand the program to all levels of play across Canada.

In addition to Rugby Canada, Volleyball Canada, and Equestrian Canada both spoke of collecting injury information, including concussion incidence.

Volleyball Canada has focused much of its concussion data collection efforts during major national competitions. The software they have used was REDcap. It is customizable tablet-based software that allowed the user to create an electronic interface to populate a database.

There was also an end of season survey that was sent to all university programs to collect injury incidence data including concussions. While the response rate was not high, this data was helpful in uncovering some important incidence statistics regarding concussions.

Equestrian Canada tracks injury occurrences at sanctioned competitions. They used a paper and pencil format to collect information from any riders that fall or when there was an incident that officials observed that they felt deserved follow-up.

In the interviews there several references to some teams that either were using or had investigated using a private sector software (HeadCheck Health and Sideline) for tracking athlete performance which included injury tracking. Some of these programs were costly which prohibited widespread use. In addition, a few people noted they had heard that some of the private sector offerings failed to live-up to the promise of being a means to assist the team in its performance development or injury management.

A few sport associations noted that they were either working with or knew of leagues working with Parachute Canada in the development of a system to track concussions. This was an IT application that teams could use to monitor sports injuries and return to play protocols for individual athletes.

Hockey Canada and Ringette Canada have some concussion data available through their insurance carriers. A study out of Simon Fraser University was looking at this data and found rates of reporting varied considerably. In addition to the incompleteness of the data, there was concern that the available data is likely focused on serious concussions.

It should be noted that none of the concussion tracking examples discussed above were done expressly to create a 'concussion passport'. With Rugby Canada, there was the potential for this to exist, but it was not the goal. The limited injury tracking in other sports was about ensuring player health in terms of a return to play program as opposed to the provision of a historical record of an individual player's concussion experience.

In the conversation around tracking concussions, it was clear there were two aspects to tracking concussion incidence. One was to track occurrences at an aggregated, anonymous level and the other was a personalized (dis-aggregated) tracking system that would maintain a record of injury incidence throughout the athlete's playing time. Based on the feedback received in the interviews, the former approach was of a higher interest and priority, albeit an anonymous (aggregated) system was recognized as not having the same impact on the health and safety of an individual athlete.

Where anonymous, aggregated data is available, it is reviewed for the sport to observe trends related to injuries and concussions. One respondent stated, "*We look at concussion and injury data collectively to help determine the viability of the particular program, rugby as an example.*" This respondent confirmed that because of the data collected, changes

have been made to particular sports programs based on the amount and type of injuries that have occurred, including concussions, specifically changes to their rugby and cheerleading programs.

Many associations, coaches, and health experts we interviewed spoke passionately of the need for aggregated incidence data for concussions in their sport. There was a near universal sentiment that not enough is known about:

- The true incidence of concussions in sport
- Understanding concussion incidence from a demographic perspective (i.e., gender, age, etc.)
- The situations when concussions are occurring (i.e., practice or competition, by position or by experience, etc.)
- Severity
- The return to play (and learning) process

Access to general, aggregated data—even a few of the data points described above—would further the understanding of concussions in sport and therefore what measures to incorporate to avoid them. And if this concussion incidence information could be provided over time it would provide those who are focused on prevention of concussions a quantifiable sense of what measures are working and which measures are not. As several people pointed out in interviews, *“Right now, without good data we are going on best practice and intuition, and hoping it is helping.”*

### **3.1.2 Issues with the Healthcare System**

Several interviewees from across all segments spoke of some aggregated tracking of concussion incidence by their respective provincial health care systems. In Ontario and Alberta, it was noted there were specific codes for concussions that could be used to understand population wide incidence.

Health care system tracking of concussions was noted by many individuals as being inadequate and problematic from an accuracy perspective. One issue identified in the discussion was that many physicians were reluctant to formally declare a concussion versus a more general head trauma injury. It was noted on numerous occasions that diagnosing a concussion was a sophisticated process and one where the science and protocols were in a state of evolution. This led many medical professionals to not be comfortable making a formal concussion diagnosis.

In some cases, we heard physicians simply neglected to take the time to code-out and provide required detail to head injuries which could be helpful from a researcher perspective. Several provincial representatives indicated there have been discussions with provincial health authorities to look at ways to improve the reporting of concussion diagnosed in the health system.

Health experts stated that while there is data existing on concussions, much of this information is fragmented across provinces or different databases and is difficult to access. Having access to a large pool of data that is organized and made available for research was believed to be extremely beneficial to the health care field.

One health interviewee said they are currently collecting data on concussions and conducting research to better understand concussion epidemiology. This respondent stated, *“We currently have a clinic with about 1,000 patients that we have concussion data on. It’s in-depth research and while it’s difficult to collect the information, it is very important. We must determine who is getting concussions, how they are being treated, and how they can be prevented. It’s about understanding the epidemiology of concussions, and this is why data is so important.”*

In one interview, the Canadian Hospitals Injury Reporting and Prevention Program (CHIRP) pediatric database for children’s injuries was referenced. In theory this was a data collection activity that had some potential to provide information on the incidence of concussions. However, it was noted in the discussion the experience with the database has not been good. The data is not regularly captured and when it is captured it is often not complete. The reason for this

was it is very challenging to get the injury data regularly and properly entered in the pediatric emergency department environment.

Another study referenced in an interview with a health expert was a national study the Canadian Institute for Health Information (CIHI) was conducting. It was to be tracking concussion reporting data in 20 hospitals across Canada.

It should be noted that none of the national efforts to track concussion data was specifically targeted at concussions in sport.

### 3.1.3 Challenges of Implementing a Concussion Tracking System

Many associations we spoke with viewed the task of developing a concussion database across their sport as very challenging, let alone developing a database that was capable of crossing multiple sporting disciplines. Privacy was a significant and often repeated hurdle to overcome--*"You have to understand this is a health record, not a sport record"*.

Several government sport representatives interviewed spoke of the challenges of accessing health-related from their own government's healthcare systems. Given the difficulties and restrictions they were encountering with their own government, they could not foresee a time when concussion data could be shared cross-jurisdictional with other provinces. If this was to happen, it was noted by several interviewees that the federal government would have to take a strong lead role.

Another common challenge identified in the interviews that is preventing the establishment of a broader concussion database for sport was the logistics around how it would be compiled and maintained. Many individuals across the range of expertise said an important first question/issue to address was who is responsible for entering the data? And for many of these individuals, there was no good answer to this question.

From an association and coach perspective, the onus of entering the injury information and keeping it updated would be the responsibility of the athlete or the athlete's parent depending on their age. There were many comments that at the grassroots level suggesting it was not feasible or possible for the coach or team official to maintain such a database—*"These are volunteers who are putting a lot of time in already so to expect them to be responsible for updating an injury registry is not going to fly."*

Some individuals felt, because of the need for a medical diagnosis of the concussion and privacy concerns it had to be the athlete and/or parents of the athlete. However, there were concerns with the approach for several reasons:

- It is not easy or convenient to access the medical system in order to attain a proper diagnosis of the head injury. Immediate access to a family doctor was very difficult which meant accessing treatment through a walk-in clinic or Emergency Department which could involve lengthy waits. Many coaches said, from experience, parents will not always take the recommendation from the coach (often another volunteer parent) to seek medical follow-up, but instead would monitor symptoms and if they did not worsen, likely not pursue medical consultation.
- If the athlete was playing at a high level of play, several interviewees noted that there would undoubtedly be some hesitation about registering a concussion into a database for fear it may hinder future athletic opportunities, selection to an elite team or scholarships or even be allowed to play in the next game.

A few government and health experts said that the tracking of the concussion information would need to be done by a team official. The rationale was this associated with membership on a team and therefore should be managed by the

team. In addition, limiting the people entering the data would ensure a consistent completion of the different fields of information.

All coaching and association representatives interviewed, along with a few government and medical experts, raised concerns of the practicality of team officials being responsible for maintaining a database. It might be doable at the elite level, but anything below this—which many made the point, is over 90% of overall sport participation—would not be possible. At the grassroots level—recreation or developmental—there are not the staff resources to be able to do this on a consistent basis.

It was pointed out on numerous occasions; these are largely volunteer positions who already provide a great deal of time to their chosen sport. In addition, at younger age levels, coaching staff often consist of parents of other participants on the team. In several interviews it was noted, other parents may not be comfortable sharing health-related information on their son or daughter with another parent.

Another challenge identified in the interviews was the cost associated with the development of a multi-sport concussion database. Several government and territorial representatives spoke of the potential financial requirement to develop and support this undertaking. They felt this would be considerable and for their respective government, this was not a high priority as an expenditure at this time. Even in Ontario, with Rowan's law in place, which calls for the eventual creation of a concussion database, it is viewed as a lower priority at this time.

It is important to note, that individuals defined 'cost' both in a financial sense but also from a human resource perspective. Many individuals raised concerns that given, from their perception, the enormity of the task to create a multi-sport concussion database, it would draw resources away from important concussion related activities currently underway.

In almost all interviews, there was reference to policies being implemented across a wide array of sports and at all levels of play that were raising awareness of concussions, improving detection training, and establishing clear return to play guidelines. These were unanimously said to be positive moves in terms of athlete safety. In many interviews it was noted that awareness/understanding of concussion in sport was a critical element ingrained in the culture of the athletes and parents if a concussion database was to have a chance at succeeding in future. As one individual noted, *"The culture around concussions is changing, but it is slow. You still hear the phrases, 'had his bell rung' or 'needs to shake that one-off' from parents and older athletes. It will take time to change attitudes regarding the seriousness of head injuries."*

Many coaches and association representatives interviewed spoke at length of the awareness and educational policies they had in place related to concussion in sport. They echoed the need for a 'cultural' shift when it comes to how athletes and even some coaches approach a concussion. For many, the fact a concussion does not represent like other sport injuries was part of the challenge. As one coach noted, *"You tear your ACL and you know it. You can't play. You are concussed you might appear OK the next day, but you're not."*

The representative from Equestrian Canada summed up the cultural sentiment needing to be overcome in a comment, *"we originated the phrase, 'get back on your horse', and now we are saying 'no, getting back on is a terrible idea'"* This comment captures a shared sentiment among many people interviewed, that it will take time to overcome the instinct of athletes to 'tough it out' and accept the fact a head injury is a severe, if not more so than other more obvious sporting injuries.

Much of the education materials around concussions in sport focused on understanding the signs of a concussion, the importance of a professional diagnosis and having a medically supported path back to playing again. Many sports covered in these interviews had defined Return to Play protocols and, in the education-related sports (high school or post-

secondary), the Return to Play was preceded by a Return to Learn policy. Many associations indicated that as part of their team or coaching accreditation process, concussion education was a mandatory requirement.

It was a widely held belief among interviewees that the efforts to-date on concussion education initiatives were important and making a difference. Some concern was expressed that the pandemic, which interrupted play in many parts of the country and for many sports, broke some of the momentum that had been building with concussion awareness activity. Several groups spoke of wanting to ensure, as sports eagerly return to play, these various policies are not over-looked in the process.

A few association and health expert interviewees went further on the importance of concussion education and detection protocols by stating the point should be lost in the desire for a concussion database that the current education and detection activity is a critical component of reducing incidences of multiple concussion syndrome. They noted, if all sports are able to better detect and therefore treat concussions, including managing the return to play, concussions are much more likely to be properly treated which, in turn, will reduce the risk of serious medical consequence of incurring a subsequent concussion.

From the interviewees, it was clear while there was merit in a concussion database, there was no willingness to shift any energy and activity away from the many initiatives currently underway to increase awareness, detection, and treatment of concussions in sport.

### **3.2 Benefits of a Concussion Database**

Sports organization representatives agreed that having access to an athlete's medical history of concussions via a document would be beneficial. A personal record of concussion history that is reliably maintained and accessible would help in addressing instances of multiple concussion syndrome. No one interviewed disputed that. However, there were caveats expressed given the perceived level of effort required to get to this point and could it ever be done in a manner that was able to capture virtually all concussions that occurred in sport.

A concussion database would also help with Return to Play/Learn planning as well as serve as an educational tool to understand the circumstances surrounding the occurrence of concussions. Being able to assess past concussion history (i.e., who they occurred to and how they occurred) would support efforts in the prevention of future concussions and other injuries.

In addition, some coaching individuals noted that if receiving medical assessments and clearance before returning to play were part of the reporting requirements, this would circumvent the underreporting of concussions. Interviewees said that some athletes and coaches "turn a blind eye" to concussions, especially if the opportunity to play professional sports is on the horizon. If medical intervention was a mandatory requirement, like is the case with the Blue Card system for rugby, this would be harder to do.

The notion that concussion record-keeping should be promoted as a way to keep athletes safe and healthy, as well as providing a better recovery process was discussed. The element of education was also seen as an important function of concussion tracking. One association respondent commented, *"From an educational standpoint, it's important to learn how brain injury has impacted individuals and to understand how to better support those who suffered concussions."*

Respondents in the health expert segment agreed that data collection on concussions is very important and indicated that reliable data is needed to understand how concussions are occurring, the specific circumstances in which they occur, how they are being treated, the symptoms, and the outcomes. It was agreed that while much research has been conducted regarding concussions, there is still a great deal that is not understood, and that the collection of data will help to answer

many questions that surround the physiology of concussions and their long-term impacts. In addition, respondents indicated that data is needed to help develop evidence-based treatments.

It is noteworthy that several experts said that the risk of experiencing a second concussion is greater when a person has had a concussion previously. This was an important rationale supporting a system to track concussion experiences.

Other health experts were more equivocal regarding the link between a first concussion and the likelihood of experiencing a second. For these individuals the linkage was not as clear, which did not lessen the need for data. However, they felt some ability to track concussion incidence and circumstances around these occurrences would help inform the linkage between multiple concussions.

One of the main challenges surrounding concussions is that they are under reported due to lack of diagnosis and/or recognition. One expert suggested that up to a third of concussions go un-reported. This creates challenges surrounding the understanding of concussion epidemiology.

The conversation regarding the merits of a concussion database inevitably elicited comments about benefits of personalized data for tracking concussions by the player and aggregated data collection, anonymously collected broadly across multiple sports and at different levels of play.

While the former would have a more direct impact on keep an individual player safe, particularly from multiple concussion syndrome, the benefits of the latter data collection approach were emphasized often by experts as to not be understated. Reliable aggregated data, as noted earlier, was viewed as not in good supply. This data would be very helpful to guide future decisions to lower concussion incidence in different sports. In addition, if made available on a longitudinal basis, it would help researchers understand what measures are working and which ones are not.

There was some discussion regarding what data needs to be captured to be useful. Researchers will want as much as possible. More is better, but this will likely stop the effort in its tracks. At a minimum, it was noted by a few researchers that the following would be required for a tracking database:

- Healthcare #
- Date of concussion
- Certified by
- Treatment in terms clearance – medically fit

It was noted by a few individuals that we spoke to that some researchers will want a large volume of information, including medical detail regarding the original injury along with treatment steps, circumstances leading to the injury, demographic information, years active in sport detail and potentially other data points. More information was viewed as having a benefit to concussion research, but it would also heighten the challenges of collecting this information and the privacy concerns associated with management of the database.

### **3.3 Concerns with a Concussion Database**

Many of those interviewed believed that medical information should only be made available to medical staff and athletic therapists, at most. This presented a problem when probed on how this would work outside the elite level of play where these teams' support staff are absent.



Privacy concerns were top of mind and respondents believed that limiting those who have access to personal medical information was the best approach.

The privacy issue would make it difficult to get the complete participation of players. Some parents will be reluctant to participate in a concussion tracking registry and decide to opt out. The idea of making participation in a concussion monitoring program mandatory was met with concern by several associations. They spoke of already too many barriers to participation in some sports.

This led to a few discussions about how a possible concussion database and general concussion information is presented to the public. There was a concern that over-stating the risks associated with concussions would result in athletes or their parents opting to not participate in the sport. This topic produced some good conversation from some coaches and associations about ensuring information about concussions emphasizes that when detected and properly treated, they are fully treatable like any other sporting injury.

Much of the interview discussion on the question focused who would have access to information. From a government and health expert perspective, assuming privacy concerns could be addressed, it was felt coaches would require access in order to make decisions on the fitness of athletes to practice and compete. As with the Rugby Canada system, coaches would need to be alerted in some manner that one of their athletes had suffered a concussion and therefore would need to be cleared for further activity.

Interestingly, many coaches expressed concern about coaches having access to historical injury information of their players. They suggested this could influence, possibly unfairly, how they play players. Several coaches raised the scenario of a volunteer coach at the youth level opting to not play an athlete because of a concussion concern. This decision, however, may not be agreed to by the athlete or the athlete's parents which may lead to an uncomfortable situation for that volunteer coach.

It was also mentioned that improved communication between medical staff, athletic therapists, and coaches is required. For example, one respondent commented, *"I will say that there needs to be better communication between our medical staff and the coaches, especially because there is often a lot of friction between the two. The coaches want the athletes to be able to play and they often think the medical team is being too cautious. I think it's important for there to be more education for the coach's concerning concussion and their impact."*

There was also concern expressed about the presence of a historical concussion record for an athlete and the risk this was accessible to elite level coaches or recruitment staff. Several elite level coaches were candid in their comments that this information could be used in the selection of athletes for their program. As one coach noted, *"given the choice between two players of equal talent, but one with a record of two or three concussions and one without, I'll take the one without. Why wouldn't you?"*

Many individuals (coaches and associations) also suggested that athletes themselves would worry about the occurrence of the situation outlined above and may be hesitant about being forthcoming with concussion information. This could potentially undermine the database.

### **3.4 Utility of QR Code Access**

The subject matter experts interviewed had mixed reactions to the idea of using a QR code system to store concussion data. Initial reactions prompted several questions regarding execution, including how the QR code system would be organized and what information would be accessible.

There was a link to the COVID-19 vaccine passport approach and the QR codes employed with that card in many provinces. Several coaching and association representatives noted that if it simply showed green for clear and red for not clear then perhaps it would be useful. There were still questions about who has the scanner and when the scanning would occur—*“did players show up with a card before each practice or game and have to scan in?”*

A common concern voiced was if people would be willing to participate if it was that easy to access. Respondents suspected that there would most likely be hesitancy around the adoption of such a system. One respondent commented, *“My question would be, would people be into something like this? It would also be really reliant on the end user [athlete] to disclose concussion information and I’m not sure that is actually the best approach since concussions are greatly underreported.”* Other respondents also had the concern that relying on a self-reporting system would not be very effective. There were also concerns surrounding privacy and people’s hesitancy to share medical information.

A few government and health officials raised concerns about the expense and whether, technically, a system can be built that is easily updatable, secure, and reliable.

A common reaction to the QR code was that it seemed to be a technically, efficient solution, however, it would not change the fact that there would be numerous and big challenges to overcome to get a system up and running so that those athletes, across multiple sports and at different level, could update it regularly with their concussion information.

# Appendix

## A.1 Qualitative Methodology – Focus groups

Léger conducted a series of ten online focus group sessions with French-speaking and English-speaking Canadians. Conducting the groups online offered the opportunity to regroup people from all the regions in Canada. Four focus groups were held with adults playing an organized sport, three focus groups were held with youth playing an organized sport and three focus groups were held with parents who have kids playing an organized sport. Two groups were held in French, and the eight other groups were held in English. For each online focus group, ten participants were recruited by our professional recruiters. A total of 91 recruits participated in the online focus groups (see Table 4 for details). All participants in the focus groups received an honorarium of \$100.

The focus groups were conducted online using Focus Vision's CMNTY platform. This platform allowed for video conferencing groups, observers in a separate virtual room, chat between participants and the moderator, and chat between the observation room and the moderator. Each group were 90 minutes long, to ensure the participation of each participant.

All sessions allowed for remote viewing by Léger observers.

Table 4. Details of the focus groups

Session Detail	Date	Recruits	Participants	Language
Adults – Atlantic	March 23	10	8	English
Adults – Quebec	March 23	10	9	French
Adults – British Columbia	March 24	10	9	English
Adults – Territories	March 24	10	9	English
Youth – Ontario	March 28	10	8	English
Youth – Prairies	March 28	10	9	English
Youth – British Columbia	March 29	10	10	English
Parents – Quebec	March 29	10	10	French
Parents – Ontario	March 30	10	9	English
Parents – Prairies	March 30	10	10	English

Recruitment was carried out by professional recruiters. The recruitment guide (available in the Appendix B) ensured that the participants met the profiles sought for each session and that they were equipped to participate in an online discussion session. To do so, they had to confirm that they had a high-speed Internet connexion, a computer, or a laptop.

### Moderation

All focus group sessions were moderated and supervised by a senior Léger researcher assisted by a research analyst. The discussion guide (available in the Appendix C) consisted of a semi-structured discussion guide. It allowed the moderator to follow the thread of the discussion and ensured that an array of themes was covered while leaving sufficient room for the participants to express themselves and develop in detail their experiences, ideas, opinions, and perceptions.

This qualitative portion of the research provides insight into the opinions of a population, rather than providing a measure in percent of the opinions held, as would be measured in a quantitative study. The results of this type of research should be viewed as directional only. No inference to the general population can be done with the results of this research.

## **A.2 Qualitative Methodology – In-depth interviews**

As part of PCH (Sport Canada)'s study into the development of a national database to track concussions that occur in sport, in-depth interviews were conducted with a select group of subject matter experts.

Léger was responsible for the recruitment and scheduling of the individuals for this study. The list of interviewees was provided by PCH (Sport Canada). Interviewees had been contacted in advance by the Department alerting them to the pending contact by Léger and the reason for the interview. The study population was organized broadly into the following categories:

- National/Provincial/Territorial Sport Organizations
- Government Representatives
- Coaches
- Health Experts

The interviews followed a structured questionnaire that was designed by Léger using an outline provided by PCH (Sport Canada). Forty interviews were conducted by a senior Léger professional and took on average approximately 45 minutes to complete.

The interviews were conducted in the language of the interviewees' choice (French/English).

### **Moderation**

All in-depth interview sessions were moderated and supervised by a senior Léger researcher assisted by a research analyst. The discussion guide (available in the Appendix C) consisted of a semi-structured discussion guide. It allowed the moderator to follow the thread of the discussion and ensured that an array of themes was covered while leaving sufficient room for the participants to express themselves and develop in detail their experiences, ideas, opinions, and perceptions.

This qualitative portion of the research provides insight into the opinions of a population, rather than providing a measure in percent of the opinions held, as would be measured in a quantitative study. The results of this type of research should be viewed as directional only. No inference to the general population can be done with the results of this research.

## A.3 Screening Guide

### DISCUSSION GROUPS DESCRIPTION

The discussion groups will be held online via Focus Vision Platform.

The target population for this whole research project is comprised of three main groups of Canadians: Adults (25+) and youth (16-24) taking part in organized sports and parents of organized sports participants.

The objective is to recruit 10 participants per discussion group.

		PARTICIPANT PROFILE
<b>ADULTS</b>	GR 1 = ATLANTIC (ENG) GR 2 = QUEBEC (FRA) GR 3 = BRITISH COL. (ENG) GR 4 = TERRITORIES (ENG)	<ul style="list-style-type: none"> <li>• Adults over 18 (varied sociodemographic)</li> <li>• Gender: a good mix</li> <li>• Language spoken: English OR French depending on the region</li> <li>• Age group: a good mix (25- 65)</li> <li>• Education: a good mix</li> <li>• Occupation: a good mix</li> <li>• Income: a good mix</li> <li>• Taking part in organized sports – before the pandemic and expect to resume the activity</li> </ul>
<b>YOUTH</b>	GR 5 = ONTARIO (ENG) GR 6 = PRAIRIES (ENG) GR 7 = BRITISH COL. (ENG)	<ul style="list-style-type: none"> <li>• Youth 16-24 (varied sociodemographic)</li> <li>• Gender: a good mix</li> <li>• Language spoken: English</li> <li>• Age group: a good mix (16-24) half and half under – upper 18</li> <li>• Education: a good mix</li> <li>• Occupation: a good mix</li> <li>• Income: a good mix</li> <li>• Taking part in organized sports – before the pandemic and expect to resume the activity</li> </ul>
<b>PARENTS</b>	GR 8 = QUEBEC. (FRA) GR 9 = ONTARIO (ENG) GR 10 = PRAIRIES (ENG)	<ul style="list-style-type: none"> <li>• Adults over 18 (varied sociodemographic)</li> <li>• Gender: a good mix</li> <li>• Language spoken: English OR French depending on the region</li> <li>• Age group: a good mix</li> <li>• Education: a good mix</li> <li>• Occupation: a good mix</li> <li>• Income: a good mix</li> <li>• Having at least minimal involvement in their child's sport (attending practices, games, competitions, involvement in the club or in club activities)</li> </ul>

For each participant, collect the following information:

Participant name:

Phone number at home:

Cell phone:

Email address:

Recruitment date:	Recruiter:
Group #:	Confirmation (date):

**STEP 1 (WEB) – SCREENING AND PROFILING**

**INTRO**

Hi, I'm \_\_\_\_\_ of Léger, a public opinion company. We are currently organizing discussion groups on behalf of the Government of Canada. The objective of the discussion group is to collect opinions and perceptions about **organized sports in Canada**. You don't need to be an expert to participate in these focus groups.

We are preparing to hold a few discussion groups with Canadians like you. These discussion groups will be conducted "online" and will be led by a research professional with up to ten participants. All opinions will remain anonymous and will be used for research purposes only in accordance with laws designed to protect your privacy. We don't have anything to sell, and we don't advertise and it is not an opinion poll on current events or politics.

Your participation is voluntary. All information collected, used and/or disclosed will be used for research purposes only and the research is entirely confidential. We are also committed to protecting the privacy of all participants. The names of the participants will not be provided to any third party. May I continue?

[INTERVIEWER NOTE: IF ASKED ABOUT PRIVACY LAWS, SAY: "The information collected through the research is subject to the provisions of the Privacy Act, the legislation of the Government of Canada, and to the provisions of relevant provincial privacy legislation.]

The discussion group will take place online on the (INSERT DATE/TIME) and will be a maximum of **1.5 hours**. You will be compensated **\$100** for your time.

**Q0**

Are you available to participate in this focus group at **INSERT DATE/TIME**?

Yes	1
No	2 <b>THANK AND TERMINATE</b>

**A1. Are you interested in participating?**

Yes	1	<b>CONTINUE</b>
No	2	<b>THANK AND TERMINATE</b>

I would now like to ask you a few questions to see if you meet our eligibility criteria to participate.

A2. The group discussions we are organizing are going to be held **over the Internet**. They are going to be "online focus groups". Participants will need to have a **computer**, a **high-speed Internet connection**, and a **WebCam** in order to participate in the group. Would you be able to participate under these conditions?

Yes	1	<b>CONTINUE</b>
No	2	<b>THANK AND TERMINATE</b>

## PROFILING

### Parents

In normal times, so we refer also before the pandemic, are you a parent, step-parent or guardian to a child or children that are involved in organized sport as a participant, and intend to continue to participate in an organized sport once the pandemic is over?

*An organized sport is one that is structured in some manner with coaching, established rules and schedule for games or events. There is often a governing body overseeing the sports affairs.*

Yes	1	CONTINUE
No	2	GO TO SPORTS1

### Parents2

Do you or do you not play the following roles in your child(ren)'s sports?

- A. I attend my children's practices
- B. I attend my children's competitions
- C. I attend parent meetings with my child's club and coaches
- D. I am involved in my child's sports club (volunteer coach, fundraising, accompanying children to competitions, organizing team tours, etc.)

Yes	1 ELIG GR-8-9-10	CONTINUE
No	2	GO TO SPORTS1

**Must have at least one yes to be eligible for the "parent" group**

### SPORTS1

In normal times, so if we refer also before the pandemic, have you been involved in organized sport as a participant, coach, instructor, official or volunteer and intend to continue to participate in an organized sport once the pandemic is over?

*An organized sport is one that is structured in some manner with coaching, established rules and schedule for games or events. There is often a governing body overseeing the sports affairs.*

Yes	1 ELIG GR1-2-3-4-5-6-7	CONTINUE TO SPORT2
No	2	THANK AND TERMINATE

### SPORTS2

**In which capacity you have participated in organized sport in Canada?**

Participant	1
Coach/Instructor	2
Volunteer	3
Administrator	4
Official	5
Other (specify)	0 96

**SPORTS3**

**What is the sport?**

96 : \_\_\_\_\_

**Example of organized sport but not limited to:**

**Boxing, Rugby, Football, Curling, Water polo, Volleyball, Judo, Equestrian, Skate, Ski, Snowboard, Hockey, etc.**

**IF NOT AN ORGANIZED SPORTS – UNORGANIZED SPORTS** Are loosely organized sports not regulated by a governing body **AND** have undefined or unclear rules. **THANK AND TERMINATE**

**INJURY HISTORY (No quotas on INJURY)**

**Parents:** Has your child ever suffered a sports injury?

**IF YES: What type of injury was it? SPECIFY:** \_\_\_\_\_

**Youth and Adults:**

Have you ever suffered an injury in the practice of your sport?

**IF YES: What type of injury was it? SPECIFY:** \_\_\_\_\_

**INTRO1. Socio-demographic questions**

1. Do you or anyone in your immediate family work or have you ever worked in ...?

Marketing Research	1 <b>THANK AND TERMINATE</b>
Marketing and Advertising	2 <b>THANK AND TERMINATE</b>
Public relations, communications	3 <b>THANK AND TERMINATE</b>
Media (newspapers, television, radio, etc.)	4 <b>THANK AND TERMINATE</b>
Telecommunications	5 <b>THANK AND TERMINATE</b>
None of the above	9

The following questions is about sex. The Government of Canada takes Canadians' privacy very seriously. This information is only being collected because sports are currently activities often organized by the categories of men and women. Your responses to these questions are confidential and you may opt to not provide a response.



**Sex**

2. 1. What was your sex at birth?

... a man	1
... a woman	2
Prefer not to say	3

**Province**

3. In which province or territory do you live?

British Columbia	1	Gr3-7
Alberta	2	Gr6-10
Saskatchewan	3	Gr6-10
Manitoba	4	Gr6-10
Ontario	5	Gr 5-9
Quebec	6	Gr2-8
New Brunswick	7	Gr1
Nova Scotia	8	Gr1
Prince Edward Island	9	Gr1
Newfoundland	10	Gr1
Northwest Territories	11	Gr4
Yukon	12	Gr4
Nunavut	13	Gr4

**4. Area**

4. Do you currently live in a urban or rural area?

Urban	1
Rural	2

**Ensure a good mix in the group****5. Language**5. What is your *first official language spoken*?

French	1	
English	2	

**6. AGE.**

6. What age category do you fall into?

Under 16	99	<b>THANK AND TERMINATE</b>
16 to 17	1	Eligible for GR 5-6-7-
18 to 24	2	Eligible for GR 5-6-7-8-9-10
25 to 34	3	Eligible for GR 1-2-3-4-8-9-10
35 to 44	4	Eligible for GR 1-2-3-4-8-9-10
45 to 54	5	Eligible for GR 1-2-3-4-8-9-10
55 to 64	6	Eligible for GR 1-2-3-4-8-9-10
65 and over	7	Eligible for GR -8-9-10

## 7. EDUCATION.

7. What is the highest level of education you completed?

Some high school or less	1
High school diploma or equivalent	2
Registered Apprenticeship or other trades certificate or diploma	3
College, CEGEP or other non-university certificate or diploma	4
University certificate or diploma below bachelor's level	5
Bachelor's degree	6
Postgraduate degree above bachelor's level	7

## 8. OCCUPATION

8. Which of the following categories best describes your current employment status? Are you...

Working full-time (35 or more hours per week)	1
Working part-time (less than 35 hours per week)	2
Self-employed	3
Unemployed, but looking for work	4
A student attending school full-time	5
Retired	6
Not in the workforce (full-time homemaker, full-time parent, or unemployed and not looking for work)	7
Other employment status. Please specify.	8

## 9 – INCOME

Which of the following categories best describes your total household income? That is, the total income of all persons in your household combined, before taxes.

Under \$20,000	1
Between \$20,000 and just under \$40,000	2
Between \$40,000 and just under \$60,000	3

Between \$60,000 and just under \$80,000	<b>4</b>
Between \$80,000 and just under \$100,000	<b>5</b>
Between \$100,000 and just under \$150,000	<b>6</b>
\$150,000 and above	<b>7</b>

#### 10. DISABILITY

Do you identify as a person with a disability? A person with a disability is a person who has a long-term or recurring impairment (such as vision, hearing, mobility, flexibility, dexterity, pain, learning, developmental, memory or mental health-related) which limits their daily activities inside or outside the home (such as at school, work, or in the community in general).

Yes	1	<b>At least one per gr</b>
No	2	
[Do not read] Don't know	98	
[Do not read] Prefer not to answer	99	

#### 11. Disability2 (IF YES AT Q10)

What type of disability are you living with?

Physical	<b>1</b>
Mental	<b>2</b>
Intellectual	<b>3</b>
Cognitive	<b>4</b>
Learning	<b>5</b>
Communication	<b>6</b>
Sensory	<b>7</b>
Other, please specify: _____	<b>8</b>
Prefer not to say	<b>9</b>

#### Privacy Notice

The personal information you provide to the Government of Canada is governed in accordance with the *Privacy Act*. We only collect the information we need to conduct the research project.

**Purpose of collection:** We require your personal information to determine your eligibility and record your consent to participate in this research.

**Other uses or disclosures:** Your personal information will not be shared. In limited and specific situations, your personal information may be disclosed without your consent in accordance with subsection 8(2) of the *Privacy Act*.

**Do you consent to participate in this research?**

- Yes (continue)**
- No (STOP)**

**Participant Name:** \_\_\_\_\_

**Date:** \_\_\_\_\_

**INVITATION**

Thank you. We'd like to invite you to participate in the discussion group.

The discussion group will take place at [XX], on \_\_\_\_XX\_\_\_\_ (date/time) \_\_XX\_\_.

Just a quick reminder that you will need a computer, a high-speed Internet connection in order to participate in the chat group. You cannot participate using a mobile phone.

Representatives from the Government of Canada and research analyst may observe the discussion group, but will not have access to any of your personal information. Do you consent to participate in this discussion group ?

Yes	1
No	2 <b>THANK AND TERMINATE</b>

Now I have a few questions that relate to privacy, your personal information, and the research process. We will need your consent on a few issues that enable us to conduct our research. As I run through these questions, please feel free to ask me any questions you would like clarified.

We need to provide the **online platform** and **session moderator** with the names and profiles of the people attending the discussion group because only the individuals invited are allowed in the session and the facility and moderator must have this information for verification purposes. Please be assured that this information will be kept strictly confidential.

**GO TO P1**

P1) Now that I've explained this, do I have your permission to provide your name and profile **to the online platform and moderator?**

Yes	1 GO TO P2
No	2 <b>THANK AND TERMINATE</b>

P2) A recording of the discussion group session will be produced for the research project purposes. The recording will only be used by **the team of people working on the project at Léger and the Government of Canada** to assist in preparing a report on the research findings.

Do you agree to be recorded for research purposes only?

Yes	1 COMPLETE THE INVITATION
-----	---------------------------

No	2 <b>Read information below and P2A</b>
----	---

It is necessary for the research process for us to record the discussion group session as the researcher needs this material to complete the report.

P2a) Now that I've explained this, do I have your permission for recording the discussion group?

Yes	1 COMPLETE THE INVITATION
No	2 <b>THANK AND TERMINATE</b>

As we are only inviting a small number of people to take part, your participation is very important to us. If for some reason you are unable to participate, please call so that we can get someone to replace you. You can reach us at \_\_\_\_ at our office. Please ask for \_\_\_\_.

We will send your login information to the online chat group to your email address. Please confirm receipt of this information when it reaches you.

Your email address : \_\_\_\_\_

**Thank you very much!**

Name:

Phone number (during the day):

Phone number (during the evening):

Email address:

## A.4 Discussion Guides

### FOCUS GROUPS

Total anticipated time per group: 90 minutes

#### Introduction and explanation

##### WELCOME AND PRESENTATION

Hello everyone and welcome to this discussion group. I hope everyone is doing well. Let me introduce myself, my name is \_\_\_\_\_ and I am \_\_\_\_\_ with Léger Marketing. Léger Marketing is a public opinion and consumer research firm. Some of you probably already know Léger Marketing from our surveys and our presence in the various media across the country. In addition to surveys, we organize discussion groups, like this one, on a variety of different topics.

##### PRIMARY AIM

Léger Marketing is conducting discussion groups for Canadian Heritage (Sport Canada) to obtain your opinions and perceptions on a few issues affecting organized sport in Canada.

##### RULES OF DISCUSSION

Even though you may not be able to see them, I did want to advise you that we do have some of our analyst colleagues participating in this study. They will be listening to the discussion group and will be taking notes.

Discussion groups are designed to encourage open and honest discussion. My role as moderator is to guide the discussion and encourage everyone to participate. I will also ensure that the discussion stays on topic and stays on schedule.

Your role is to answer questions and express your opinions. We want to hear everyone's opinions in a discussion group, so don't hold back if you have a comment even if you think your opinion may be different from others in the group. Others may share your point of view. Everyone's opinion is important and should be respected.

I would also like to emphasize that there are no wrong answers. We are simply looking for your opinion. This is not a test of your knowledge.

It is also important that you speak loud enough so that everyone can hear you and that you speak one at a time so that I can follow the discussion.

Finally, we are video recording the discussion group for analysis purposes. The recording will only be viewed by the individuals working on this project to help them write a project report for Canadian Heritage (Sport Canada). The recordings will not be circulated in any other way without your explicit consent.

##### RESULTS CONFIDENTIALITY

- The discussions we will have this evening will always remain confidential.
- Your name will never be mentioned in the project report.
- Information is being collected for the project purposes only.

Do you have any questions before we get started?

## **A. PARTICIPANTS – ADULTS AND YOUTH**

### **Ice-breaker Task:**

To start off, please introduce yourself by sharing your first name and the organized sport(s) in which you are involved, whether as a participant, coach, organizer, referee, etc., with the rest of the group.

We are now going to start the question-and-answer portion which is our main reason for being here today.

### **Part 1: Introduction to Head Injuries in Sport**

*\*\*\*For the purposes of this discussion, please note that the term 'sport' refers to 'organized sport' which defined as "Organized sport is generally officiated, has a regular schedule, and is governed by rules. A few examples are a community soccer program, swim team or athletics club." \*\*\**

I would like to know if you consider your sport to be a slightly dangerous or very dangerous, in the sense that there is a high risk of injuries or accidents?

What types of injuries or accidents are most common in the sport(s) you play?

Have you ever been injured or had an accident while playing your sport(s)? What kind of injury or accident have you experienced?

Have you experienced any head injuries while playing your sport(s)? Is there a high or low probability of you sustaining a concussion(s)? Why is that the case, please explain your answer? Are there more or less risks of concussions in the sport(s) you play than in other sports?

Have you ever suffered a concussion? Once or more than once?

If not, have you ever witnessed another participant sustain a concussion?

### **Part 2: Management of concussion**

What was it like managing your recovery from the concussion you sustained?

Who was involved in this management? Was it well managed from your perspective?

What were everyone's responsibilities? The doctors? The coaches? Parents or family? The club or the league?

Do you feel that your family handled the management aspect of your concussion to the best of their abilities? Please explain your answer.

Was a medical document or record (e.g., a medical note from the doctor or a medical assessment providing an overview of the head injury sustained with the prescribed treatment etc.) of your concussion shared with your club, league, coaches, or your family and who shared it?

What kind of information was included in this record?

What happened with this record?

What is it supposed to be used for? How could it be used?

Did you have any negative experience(s) with sharing this information with the coach and/or club?

Looking back at the concussion sustained, the management of it and your recovery experience, do you now have any concerns about continuing to play sports in the future?

Do you have concerns about the possibility of sustaining additional concussions and what are they?

### **Part 3: Introduction of the Concussion Passport**

Let us now explore a hypothetical situation.

The scenario is as follows: Visualize that there is a medical document or record that captures the information of an individual's (or participant's) concussion history (which would include current and previous concussion events). This would be a personal document for each participant.

If asked, would you agree to share your medical history of concussions with coaches and sport organizations/clubs via a document (e.g., a health passport) to ensure measures are in place to protect your health?

Why? Can you explain your answer?

What makes you say yes?

What makes you say no?

In the future, if a health passport with your concussion history existed would you be comfortable sharing this document with your sport organization? Do you think that this would help your sport organization/club implement the appropriate measures to protect your health when you returned to play post-concussion? Please explain your answer.

Do you see any advantages and/or benefits associated with such a document?

Why do you say this?

### **Part 4: Concerns**

How do you feel about sharing your medical concussion history with your sport organization/club?

Can you explain your feelings about it?



IF YES: What are your main concerns? Why? Are there any other concerns?

IF NO: Why do you say that? Can you tell why you don't have any concern?

IF NOT MENTIONED PREVIOUSLY:

What are your concerns when it comes to the organization's management of your medical concussion history (captured in a health document)?

Please explain your concerns.

**Explore in depth any concerns participants may have about sharing their medical records with their sport organization/club.**

## **Part 5. Conclusion**

That wraps up the questions I had for you today. I would like to know if you have any other comments about the idea of a medical concussion passport in organized sports.

Any other ideas you would like to share before we end this session?

Prompt: Would something like the COVID-19 Passport be relevant?

**THANK YOU FOR YOUR PARTICIPATION.**

## **B. PARENTS OF PARTICIPANTS**

### **Ice-breaker Task:**

To start off, please introduce yourself by sharing your first name and the organized sport(s) your child(ren) participates in. Also let us know if you play a role in your child's sport (whether as a coach, trainer, manager, volunteer, referee, etc.)

We are now going to start the question-and-answer portion which is our main reason for being here today.

### **Part 1: Introduction to Head Injuries in Sport**

*\*\*\*For the purposes of this discussion, please note that the term 'sport' refers to 'organized sport' which defined as "Organized sport is generally officiated, has a regular schedule, and is governed by rules. A few examples are a community soccer program, swim team or athletics club." \*\*\**

I would like to know if you consider the sport, in which your child(ren) participates, to be slightly dangerous or very dangerous, in the sense that there is a high risk of injuries or accidents?

What types of injuries or accidents are most common in the sport(s) in which your child(ren) participates?

Has\Have your child(ren) ever been injured or had an accident while participating in their sport(s)? What kind of injury or accident has/have they sustained?

Has\Have your child(ren) experienced any head injuries while playing their sport(s)?

Is there a high or low probability of them sustaining a concussion(s) in their sport(s)? Why is that the case, please explain your answer? Are there more or less risks of concussions in the sport(s) they play than in other sports?

Has\Have your child(ren) ever suffered a concussion? Once or more than once?

If not, have you ever witnessed another child participant sustain a concussion?

## **Part 2: Management of concussion**

What was it like managing your child(ren) recovery from the concussion they sustained?

Who else was involved in your child(ren) concussion management?

What was involved in their concussion management?

What were everyone's concussion management responsibilities? The doctors? The coaches? Parents or family? The club or the league?

Was a medical document or record of your child(ren) concussion shared with you, the club, the league, or the coaches? What information related to your child's concussion did you share with your child's coaches and/or sport organization?

What type of information was included in this medical document or record?

How was this information in the record used? What happened with this record once your child was cleared to go back to playing their organized sport?

Did you have any negative experience(s) with sharing this information with the coach, sport organization and/or club?

## **Part 3: Introduction of the Concussion Passport**

Let us now explore a hypothetical situation.

The scenario is as follows: Visualize that there is a medical document or record that captures the information of an individual's (or participant's) concussion history (which would include current and previous concussion events). This would be a personal document for each participant.

If asked, would you agree to share your child(ren)'s medical history of concussions with coaches and sport organizations/clubs via a document (e.g., a health passport) to ensure measures are in place to protect their health?

Why? Can you explain your answer?

What makes you say yes?

What makes you say no?

In the future, if a health passport containing your child(ren)'s concussion history existed would you be comfortable sharing this document with their sport organization/club? Do you think that this would help their sport organization/club implement the appropriate measures to help protect the health of your child(ren) when they return to play post-concussion? Please explain your answer.

Do you see any advantages and/or benefits associated with such a document?

Why do you say this?

#### **Part 4: Concerns**

Would you be willing to share your child(ren)'s medical concussion history in the form of a concussion passport?

How do you feel about sharing this information sport organization/club?

Can you explain your feelings about it?

IF YES: What are your main concerns? Why? Are there any other concerns?

IF NO: Why do you say that? Can you tell why you don't have any concern?

IF NOT MENTIONED PREVIOUSLY:

What are your concerns when it comes to the organization's management of your child(ren)'s medical concussion history (captured in a health document)?

Please explain your concerns.

**Explore in depth any concerns participants may have about sharing their child(ren)'s medical records with their sport organization/club**

Do you feel that your sport organization is equipped to manage concussion information? Please explain your answer.

#### **Part 5. Conclusion**

That wraps up the questions I had for you today. I would like to know if you have any other comments about the idea of a medical concussion passport in organized sports.

Any other ideas you would like to share before we end this session.

Prompt: Would something like the COVID-19 Passport be relevant?

**THANK YOU FOR YOUR PARTICIPATION.**

# IN DEPTH INTERVIEWS

## INTRODUCTION

- Introduce the moderator and Léger Marketing
- Identify sponsor of the research and broad objectives - PCH (Sport Canada)
- Broadly explain who else is being interviewed
- Meeting duration – about half hour to 45 minutes
- Format for conversation
- Audio recording (with permission)
- Anonymity in reporting and the report will be publicly available on Library of Parliament website when complete

## OBJECTIVE

Data is needed to gain a fuller understanding of the Canadian public's perceived value, benefits, interest, and concerns on the implementation of a concussion passport in sport. This research will also complement and build on current concussion-related quantitative data findings from the PCH (Sport Canada) 2021 Safety, Ethics, Equity in Sport Survey. It will help guide future directions of Government of Canada support and leadership in the areas of concussion management and prevention as well as directly inform the work of the Federal-Provincial and Territorial (F-P/T) Concussions Working Group (co-chaired by PCH Sport Canada) and the F-P/T Sport, Physical Activity and Recreation Ministers.

## NATIONAL/PROVINCIAL/ TERRITOTIAL SPORT ORGANIZATIONS

### Q1

Is your sporting organization doing any data collection on concussions (e.g., occurrence of, history of individuals)?

PROBE FOR DETAILS IN DISCUSSION

IF YES: What does that look like? How are you gathering the data? Why are you gathering this information?

IF NO: Have you considered something to track concussions? Why not? [IF NECESSARY & DECISION NOT TO] Why did you decide not to go this route?

IF IN DEVELOPMENT: Please describe what you are doing?

### Q2

Would you agree that it would be helpful to the organization and to the coaches to have access to an athletes' medical history of concussions via a document (e.g., a concussion health record) to ensure measures are in place to protect their health?

- Why do you say that?
- What are the benefits?
- Are there concerns? [IF SO] What are your concerns?

**Q3** [MAY HAVE BEEN DISCUSSED IN Q2 ABOVE]

Do you have any concerns with medical history of concussion(s) being captured in a document (e.g., a health record or account)?

IF YES: Please explain what your concerns are. Can this be mitigated somehow?

**Q4**

Would using a QR code similar to the COVID system be an option to store concussion data?

- Are there concerns with this? TRY TO LIST CONCERNS
- Who do you see as having access?
- What information should be available? How much detail?

**Wrap**

That concludes my questions. Do you have anything you wanted to add to what we discussed?

Thank you. Have a good rest of your day

## **GOVERNMENT BODIES**

### **Q1**

Is your government organization doing any data collection on concussions (e.g., occurrence of, history of individuals)?  
PROBE FOR DISCUSSION

IF YES: What does that look like? How are you gathering the data? Why are you gathering this information?

IF NO: Have you considered something to track concussions? Why not? [IF NECESSARY] Why did you decide not to go this route?

IF IN DEVELOPMENT: Please describe what you are doing?

### **Q2**

In your respective jurisdiction, what would be the best mechanism to collect/manage concussion data?

- What challenges do you/ would you face if you undertook this?

### **Q3**

Do you have any concerns with the management of medical history of concussion(s) in a document (e.g., a health record)?

- IF YES: Please explain what your concerns are. Can this be mitigated somehow?

### **Q4**

Would using a QR code similar to the COVID system be an option to store concussion data?

- Are there concerns with this? TRY TO LIST CONCERNS
- Who do you see as having access?
- What information should be available? How much detail?

## **Wrap**

That concludes my questions. Do you have anything you wanted to add to what we discussed?

Thank you. Have a good rest of your day

## **HEALTH EXPERTS**

### **Q1**

Do you feel that data collection on concussions is important?

- Why do you say that?
- What would be the benefits?

### **Q2**

Which are the best mechanisms to collect and manage concussion data? Please select all that apply.

- A personal health document/record
- A database
- Something else [DISCUSS]

### **Q3**

How can the concussion data be used to prevent future re-occurrences? Please provide a detailed response.

### **Q4**

Do you have any concerns with the management of medical history of concussion(s) in a document (e.g., a health record)?

- IF YES: Please explain what your concerns are. Can this be mitigated somehow?

### **Q5**

Would using a QR code similar to the COVID system be an option to store concussion data?

- Are there concerns with this? TRY TO LIST CONCERNS
- Who do you see as having access?
- What information should be available? How much detail?

## **Wrap**

That concludes my questions. Do you have anything you wanted to add to what we discussed?

Thank you. Have a good rest of your day

## COACHES

### Q1

Is your sporting organization doing any data collection on concussions (e.g., occurrence of, history of individuals)?  
PROBE FOR DISCUSSION

IF YES: What does that look like? How are you gathering the data? Why are you gathering this information?

IF NO: Have you considered something to track concussions? Why not? [IF NECESSARY] Why did you decide not to go this route?

IF IN DEVELOPMENT: Please describe what you are doing?

### Q2

Do you have any concerns with the management of medical history of concussion(s) in a document (e.g., a health record)?

- IF YES: Please explain what your concerns are. Can this be mitigated somehow?

### Q3

Would you agree that it would be helpful to the organization and to the coaches to have access to an athletes' medical history of concussions via a document (e.g., a concussion health record) to ensure measures are in place to protect their health?

- Why do you say that?
- What are the benefits?
- Are there concerns? [IF YES] What are these? PROBE PERSPECTIVES: player; parent; coach

### Q4 [MAY HAVE BEEN DISCUSSED IN Q3 ABOVE]

Do you have any concerns with medical history of concussion(s) being captured in a document (e.g., a health record or account)?

IF YES: Please explain what your concerns are. Can this be mitigated somehow?

### Q5

Would using a QR code similar to the COVID system be an option to store concussion data?

- Are there concerns with this? TRY TO LIST CONCERNS
- Who do you see as having access?
- What information should be available? How much detail?

## Wrap

That concludes my questions. Do you have anything you wanted to add to what we discussed?

Thank you. Have a good rest of your day