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# The BRAIN-Q, a tool for assessing self-reported sport-related concussions for epidemiological studies

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Running title BRAIN-Q

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## Abstract

**Objectives** - The BRAIN-Q is a tool aimed at maximising the accuracy, and minimising measurement error, for retrospectively assessing concussions. This paper reports agreement of the BRAIN-Q tool when compared to extant questionnaire questions, and reproducibility when compared with its telephonic version (tBRAIN-Q).

**Methods** - The BRAIN-Q entails a 3-stage process: defining concussion, creating a visual timeline with life events, and establishing detailed characteristics for each reported concussion. It was designed to be administered in-person by trained personnel, and was used in the BRAIN Study. Its performance was compared with the MSK Study which previously collected a few questions in a broader self-administered questionnaire; and with the tBRAIN-Q Recall, its telephonic version.

**Results** - 101 participants were included; of these, nine were re-assessed with the tBRAIN-Q. Compared to the BRAIN-Q, the agreement with the MSK-Q for rugby-related concussion was 86.7% (kappa 0.6). Rugby-related concussion with loss of consciousness showed lower agreement (82.0% (kappa 0.6)). The comparison between the BRAIN-Q and the tBRAIN-Q showed a good reproducibility.

**Conclusions** - The BRAIN-Q is a relatively easy tool to administer in face-to-face assessments, it showed an optimal reproducibility, it includes a well-established definition of concussion, and is used to collect detailed information on each concussion allowing for a number of subgroup analyses (e.g. by severity, by age, by context). The BRAIN-Q is easily adaptable to other sporting settings

## Keywords

*Questionnaire; Evaluation; Sport-related concussion; Self-reported exposure; Epidemiological study*

## Introduction

Concussions occur as a result of trauma, and despite being recognised clinically for over one thousand years, have only been increasingly considered in sporting contexts in recent years [1]. Whilst there has been an awareness of post-concussion symptomology for many years, the prognosis for patients following concussion has had little attention until recent decades. The long-term effects of sport-related concussions are attracting increasing attention from the public and the scientific community due to the newly described Chronic Traumatic Encephalopathy (CTE) [2]. Additionally, in comparison with other sporting injuries, concussions are prominent across multiple sporting contexts, amenable to prevention and risk reduction efforts, and may predispose athletes to further risk of injury.

Increasing evidence suggests that exposure to sport-related concussions may increase the risk of neurodegenerative diseases later in life [3,4]. A recent systematic review on sport-related concussion and cognitive function concluded that the overall evidence points towards an association between sustaining a sport-related concussion and poorer cognitive function later in life in rugby, American football and boxing [5]. Despite the mounting neuropathological evidence, and some initial studies in the field of rugby [6–8], there are a number of questions that remain unanswered on the association linking the exposure to concussion to the neuropathological and the clinical prognosis.

In this context, when designing cross-sectional and case-control retrospective epidemiological studies, one of the main challenges is the assessment of self-reported exposure to previous concussion [5–8]. This is particularly true when assessing the association with poor cognitive function, as individuals suffering from cognitive decline may less accurately recall their exposure to concussion, potentially biasing the results. Adding to this challenge of retrospective exposure assessment, the definition of sport-related concussion is changing over time [9,10]. Anecdotal reports support the view that a few decades ago, loss of consciousness (LOC) was required for a head impact to be defined as a concussion. This may have resulted in an underestimation of concussion in previous studies.

Careful consideration of these challenges has led the research team of the BRain health and healthy AgeING in retired rugby union players (BRAIN) Study [11], to the development of a new tool aimed at maximising the accuracy and minimising measurement error when assessing self-reported concussion during face-to-face interviews: the BRAIN-Q tool. The aim of this paper is to report the agreement of the BRAIN-Q tool when compared to previously extant self-administered questionnaire questions, and to report its reproducibility when compared with its telephonic version (tBRAIN-Q).

## Methods

The present analysis used information on sport-related concussion which was collected with three different tools, in four partially overlapping samples of male former elite rugby players, from two previous studies (Figure 1; Table 1). All participants, for whom at least two different assessments carried out with two different tools were available for comparison, were included in this study. The studies and the tools used to assess concussion are described in detail below.

### The Studies

#### The MSK Study (Pilot and Main)

The Arthritis Research UK Centre for Sport Exercise and Osteoarthritis Rugby Epidemiology Questionnaire© is a cross-sectional questionnaire-based study, carried out by the University of Oxford within the Centre for Sport, Exercise and Osteoarthritis Versus, which assessed the general and musculoskeletal health of 319 former elite male Oxford and Cambridge University players, and English international rugby players ('MSK Study') [12]. The pilot study initially recruited former Oxford and Cambridge University rugby-playing participants using an online questionnaire (N=90), and then a modified questionnaire was produced and available postally or online, and distributed to both Oxbridge and former England international rugby playing participants (N=229). Participants were recruited between August 2014 and February 2016. The median age of the players was 62.0 (range: 24.2 to 95.0) years, with a mean playing exposure of 22.2 years ( $\pm 5.3$ ), and 83.6% were amateur players. All participants signed an informed or proxy consent to participate to the study. The study received ethical approval by the University of Oxford Central University Research Ethics Committee (MSD-IDREC-C1-2014-020).

#### BRAIN Study

The BRAIN Study is a cross-sectional study investigating the associations between self-reported concussion and cognitive function in retired elite male rugby players aged 50+ in England [11]. Participants were recruited to the BRAIN Study between April 2017 and May 2019. The majority of the BRAIN Study participants (N=101) were recruited from the earlier MSK Study, and were included in the present analysis; given that the desirable sample was not reached, a minority was recruited from a list of the England Rugby Internationals Club (ERIC) players [11]. Overall, the median age of the sample was 70 (p25-p75: 61-77) years, they had a mean length of playing career of 15.8 (SD: 5.4) years, and their position of play was 45% backs and 55% forwards. Nine of these subjects were re-assessed with the telephonic version of the

BRAIN-Q, the tBRAIN-Q tool, after the in-person assessment. For these 9 participants, the length of time between conducting the BRAIN-Q and then the tBRAIN-Q was at least 40 days. All participants signed an informed consent to participate to the study. The study was approved by the Ethical Committee of the London School of Hygiene and Tropical Medicine (EC/11634) and further approved by the other participating institution Ethical Committees.

For the purpose of the present analysis, subjects previously enrolled into the pilot and the main MSK Study (pilot, (n=14) main study, (n=87)), and subsequently enrolled into the BRAIN Study – generating two non-overlapping samples – were included in the present analysis (n=101). In addition, 9 subjects assessed twice with the BRAIN-Q and tBRAIN-Q tools were analysed (Figure 1).

## The assessment tools

### MSK Study questionnaire (MSK-Q)

The concussion data collected in the MSK Study took the format of a few questions within a broader self-administered questionnaire focussing on health, morbidity, musculoskeletal disorders and joint pain (MSK-Q). In the pilot study, the data were collected using an online questionnaire, and in the main study, data were collected using a postal or online questionnaire.

A definition of concussion was outlined on the form for both pilot and main studies, before the rugby and non-rugby related concussion questions were asked (Table 2). Following the definition, participants were asked: “Have you ever been dazed (‘dinged’) during a match?”, allowing for answers ‘yes’, ‘no’, or ‘don’t know’; and “Have you ever been unconscious (‘knocked out’) during a match?”, allowing for ‘yes’, or ‘no’. In the main study only, total number of concussions (rugby-related and non-rugby-related) were collected with the question: “How many times have you been concussed? Please include all sporting and non-sporting concussions”, allowing for the answer ‘concussed’ and ‘don’t know’ and the relative numeric answer or “don’t know”. In addition, players were asked questions on return to play, and if they had been seen by neurologist and other characteristics estimating concussion severity, which are not included in the present analysis. These questions were added to a self-administered questionnaire, and overall the time needed to complete this section by the respondent was estimated to be less than 5 minutes.

For the aim of this analysis, only the questions leading to the construction of numerical variables identifying the previous exposure to concussion and their numbers were included. Three dichotomous variables were created: rugby-related concussion, rugby-related concussion with loss of consciousness,

and any concussion (rugby-related and non-rugby-related) (yes/no), allowing for respective missing values. In addition, one numerical variable was created indicating the number of any concussions suffered. Differences in size of the sample in which each variable was available was due to differences between the pilot and the main study questionnaire (Table 1).

### BRAIN-Q Tool

The BRAIN-Q is a concussion assessment tool which was developed for the BRAIN Study, and designed to be administered in-person by a trained research assistant. Careful consideration was given in designing the tool to elicit the most accurate assessment of concussion possible: the BRAIN-Q attempted to maximise the ability to obtain accurate concussion data by incorporating three core elements. Firstly, BRAIN-Q gave a clear definition of concussion to the participant. The definition was developed using the National Institute of Health (NIH) concussion definition [13], and the language was simplified in order to make it accessible to a wider audience (Panel 1). Participants in the BRAIN Study were asked to read aloud the concussion definition before specifying the number of times they had been concussed, both during rugby and outside of rugby. Secondly, to assist the participant in recalling the number of sport-related and non-sport-related concussions he suffered during his lifetime, the BRAIN-Q offered a visual timeline. The timeline was derived on the basis of high-level questions about their playing career and life events which benchmarked some meaningful periods (e.g. school years, when started playing at varsity level, when at professional level, and during post-elite-level career). Each participant was asked to confirm their first self-reported number of concussions after using the timeline to record them. Lastly, for each self-reported concussion, the BRAIN-Q asked detailed questions on age, severity, loss of consciousness, together with some contextual information such as whether sport-related or not. Information on severity included fracture of the skull or any other head bones, admission to hospital, or evaluation in the Accident & Emergency department without overnight admission. Information on the contextual factors included if the concussion was experienced while playing/training for rugby, playing/training for another sport, motor vehicle accident or other. The time needed to complete the BRAIN-Q test was estimated to be between five and 10 minutes, depending on the length of rugby career and the number of concussions to be recorded. The full BRAIN-Q assessment tool is available as supplementary material.

For the purpose of this analysis, information from the BRAIN-Q tool was used to generate three dichotomous variables (rugby-related concussion, rugby-related concussion with loss of consciousness, and any concussion), and one discrete variable (number of any concussions suffered) (Table 1), which could be compared to the four generated MSK Study variables.

### The tBRAIN-Q Recall

The tBRAIN-Q Recall (telephonic version of the BRAIN-Q) was carried out without the aid of a timeline, and with participants who had already undertaken the BRAIN-Q assessment. The tBRAIN-Q Recall was administered in order to assess BRAIN-Q's repeatability. A subsample of 22 participants were randomly selected from the BRAIN Study (independently from any characteristics of the concussion previously reported); of these, 10 agreed to repeat the BRAIN-Q assessment by phone (tBRAIN-Q), of whom only 9 had also provided data for the MSK-Q.

During the telephone assessment, the definition of concussion provided to the participant in the original face-to-face assessment was repeated to the participants. The information collected generated the same variables as per the BRAIN-Q, displayed in Table 1.

### Data collection

In order to compare the data collected by the two tools, as mentioned previously, the concussion information from both studies was recoded, and four variables were derived which could be compared across the BRAIN and the MSK studies. These were three dichotomous variables (rugby-related concussions, rugby-related concussion with loss of consciousness, and any concussion), and one discrete variables (number of any concussion). These variables are available for the entire, or a subset of, the sample by design, and are shown in Table 1.

### Data analysis

Data available for the dichotomous variables were displayed in contingency tables; and the agreement of the MSK-Q in relation to BRAIN-Q were calculated. A Bland-Altman plot, a graphical method used for evaluating agreement between two quantitative measures [14], was produced for the discrete variable, and the limits of agreement calculated. Concordance statistics were calculated to assess the agreement between the BRAIN-Q and t-BRAIN-Q as well

## Results

A total of 101 participants who underwent the BRAIN-Q and also had concussion data recorded as part of the MSK-Q were included in the analysis. Of these, nine participants were recalled to undertake the tBRAIN-Q. Only three dichotomous and one discrete variable could be compared between the two main



studies: the rugby-related concussion, rugby-related concussion with loss of consciousness, and any concussion dichotomous; and the number of any concussions (Table 1).

The prevalence of rugby-related concussion using the BRAIN-Q was estimated to be 79% (80/101) in this sample; the same prevalence using the MSK-Q was estimated to be 80% (80/98). Similarly, the prevalence of rugby-related concussion with loss of consciousness was estimated to be 57% (58/101) in the BRAIN Study and 53% (53/100) in the MSK Study. The prevalence of any concussion using the BRAIN-Q was estimated to be 82% (83/101) in this sample; the same prevalence using the MSK-Q was estimated to be 79% (53/67).

Cross-tabulations with and agreement calculated for the dichotomous variables are shown in Table 3, Table 4, and Table 5. For rugby-related concussion the agreement between the two data collection methods of 86.7% (kappa statistic 0.6) (Table 3). The rugby-related concussion with loss of consciousness variable had a slightly lower agreement (82.0% (kappa statistic 0.6)), compared with the previous one (Table 4). A similar analysis for any concussion shows an agreement between the two tools of 88.1%; the kappa statistic 0.6 lies between moderate and substantial agreement (Table 5).

The number of any concussions collected with the two methods and compared using a Bland-Altman plot shows a level of agreement among them (Figure 2): overall the BRAIN-Q recorded a slightly higher number of concussions (mean (SD): 4.45 (3.82)) compared to the MSK-Q (mean (SD): 3.57 (3.02)), with differences between tools becoming higher with a higher number of self-reported concussions, specifically for more than 6 concussions (N=9).

The length of time (in days) between the BRAIN-Q assessment and follow-up phone call (tBRAIN-Q Recall) ranged from 40 days to just over a year (368 days), with a median (p25-p75) of 121 days (103-198 days). The comparison between the two sets of data (Table 6), shows there is little change between the concussion data collected in BRAIN-Q and by tBRAIN-Q recall, with a high concordance reported among rugby related and total number of concussions ( $\rho > 0.9$ ). This suggests that BRAIN-Q as a method for collecting concussion data is reproducible. Considering that all participants underwent the BRAIN-Q before the tBRAIN-Q recall, it is not possible to assess the tBRAIN-Q independently, nor to estimate the effect of the timeline on accuracy.

## Discussion

This is the first study evaluating a tool designed specifically to recall past exposure to sport-related concussion. The BRAIN-Q is easy and relatively fast to administer, and it showed very good reproducibility.

The prevalence of rugby-related concussion measured with the BRAIN-Q tool is comparable to that measured with a simpler self-administered questionnaire. The agreement between the two tools was higher when any concussion was considered (88.1%) , and slightly reduced for concussion with LOC (82.0%) possibly suggesting that the interpretation of what constitutes losing consciousness is now always consistent. The analysis of the number of self-reported concussions by each individual suggested that accuracy of reporting is reduced with increasing the number of concussions reported; the differences between the two methods was high for six or more concussions reported.

Strengths of the BRAIN-Q are that it is relatively easy to administer in face-to-face assessments, showed an optimal reproducibility, used a well-established definition of concussion, and collects detailed information on each concussion allowing for a number of subgroup analyses (e.g. by severity, by age, by context). Moreover, it is easily adaptable to other sporting settings. Possible weaknesses of the tool are that it cannot completely account for potential misclassification bias of people with subclinical cognitive impairment recalling their exposure to concussion in a systematically different way compared to people without cognitive impairment. Additionally, the present data are somewhat limited by small numbers, in particular for selected comparisons (i.e. the number of rugby-related concussions), and possible selection bias of the tBRAIN-Q sample which had a low response rate. The small sample size may also have affected the lack of certainty in the confidence intervals for specificity. The use of the NIH definition for concussion in the BRAIN-Q, ensures the robust capture of concussion using an established and current definition; however, as has been mentioned, the definition of concussion has evolved over recent years, it is possible that we may have limited reporting by individuals with less common symptoms, or those which are not aligned with the NIH definition. The studies in which these tools were compared both involved male former rugby playing populations. Females are at a higher risk of concussion, and implementing this tool for female samples, and in other sporting contexts, would support its generalisability outside of rugby and to more general settings.

The current results do not replicate the increase of concussion estimations which were observed after supplying a definition of concussion to the respondents from American footballers [15] and athletes from

other sports [16]. This may be due to the fact that rugby players in England tend to be a highly educated group of people, the majority of whom have studied at university level and generally show a good knowledge and understanding of the definition of concussion, and its consequence. Additionally, this could have been affected by recent rugby-led concussion awareness campaigns such as HEADCASE [17] reaching their targeted playing, parental and officiating audiences. However, it has been previously shown that player concussion knowledge may not prevent risk-taking behaviour, with 91% of Irish club and national rugby players being aware that they should not continue playing post-concussion, however 75% stating they would in an important game. O'Connell et al also found that 39% of players had tried to influence a medical assessment showing how concussion knowledge may not always be reflected in a safe behaviour [18].

In conclusion, the BRAIN-Q tool was found to improve the ability of identifying rugby-related concussion in this sample, and showed a good reproducibility when administered by phone. By using it in other studies, the consistency of results would be sensibly improved.

**Availability of data and material:** Miss Laura James and Prof Gallo had full access to all of the data in the study and takes responsibility for the integrity of the data and the accuracy of the data analysis. They declare that this manuscript is honest, accurate, and transparent account of the study being reported; that no important aspects of the study have been omitted. All co-authors had full access to the data, and can take responsibility for the integrity of the data and the accuracy of the data analysis.

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Table 1: The four concussion variables used in the analysis and how they were derived from each data source

Derived Variable	BRAIN-Q N=101	tBRAIN-Q Recall N=9	MSK Pilot N=14	MSK Main N=87
<b>Ever suffered a rugby-related concussion (yes/no)</b>  <i>Rugby-related dichotomous</i>	How many times have you been concussed whilst playing or training for rugby? (N=101)	Number of concussions (rugby and non-rugby)? (N=9)	Have you ever been dazed ('dinged') during a match? + Have you ever been unconscious ('knocked out') during a match? (N=14)	Have you ever been dazed ('dinged') during a match? + Have you ever been unconscious ('knocked out') during a match? (N=84*)
<b>Ever suffered a rugby-related concussion with loss of consciousness (yes/no)</b>  <i>Rugby-related with LOC dichotomous</i>	How many times have you been concussed whilst playing or training for rugby? + Temporary loss of consciousness (N=101)	-	Have you ever been unconscious ('knocked out') during a match? (N=14)	Have you ever been unconscious ('knocked out') during a match? (N=86*)
<b>Ever suffered any concussion (yes/no)</b>  <i>Any concussion dichotomous</i>	How many times have you been concussed whilst playing or training for rugby? + How many times have you been concussed when you have not been playing or training for rugby? (N=101)	How many times have you been concussed whilst playing or training for rugby? + How many times have you been concussed when you have not been playing or training for rugby? (N=9)	-	How many times have you been concussed? Please include all sporting and non-sporting concussions (concussed/don't know) (N=67)
<b>Number of any concussion**</b>  <i>Any concussion numerical</i>	How many times have you been concussed whilst playing or training for rugby? + How many times have you been concussed when you have not been playing or training for rugby? (N=83, ever concussed only)	How many times have you been concussed whilst playing or training for rugby? + How many times have you been concussed when you have not been playing or training for rugby? (N=9)	-	How many times have you been concussed? Please include all sporting and non-sporting concussions (N=53, ever concussed only)

\* Number differs from total allowing for "don't know" answers and missing values.

\*\* Of those that answered "Yes" to Ever Concussed

LOC= loss of consciousness

Table2: Concussion definitions provided by each assessment tool

<b>MSK-Q (main)</b>	<b>BRAIN-Q</b>
<p><i>Concussion is defined as an injury resulting from a blow to the head that caused an alteration in mental status and one or more of the following symptoms: headache, nausea, vomiting, dizziness/balance problems, fatigue, trouble sleeping, drowsiness, sensitivity to light or noise, blurred vision, difficulty remembering and difficulty concentrating.</i></p>	<p><i>Concussion is defined as an alteration in brain function, caused by an external force. Symptoms include:</i></p> <ul style="list-style-type: none"> <li>▪ <i>A decreased level / loss of consciousness</i></li> <li>▪ <i>Memory Loss (before or after the injury); Weakness / Temporary Paralysis</i></li> <li>▪ <i>Loss of balance</i></li> <li>▪ <i>Change in vision (e.g. blurriness, double vision)</i></li> <li>▪ <i>Co-ordination difficulties</i></li> <li>▪ <i>Numbness</i></li> <li>▪ <i>Decreased sense of smell</i></li> <li>▪ <i>Difficulty understanding what others are saying</i></li> <li>▪ <i>Difficulty communicating with others</i></li> <li>▪ <i>Confusion, disorientation, or slowed thinking</i></li> </ul> <p><i>Loss of consciousness is not required for a concussion to be diagnosed.</i></p>



Table 2: Cross-tabulation of the dichotomous rugby-related concussion (Yes/No) variable assessed with BRAIN-Q and MSK questionnaire

<b>Ever concussed (rugby-related)</b>		BRAIN-Q		Tot
		Yes	No	
MSK-Q – main + pilot	Yes	72	6	78
	No	7	13	20
	Tot	79	19	98

Agreement = 86.7% [kappa statistic of 0.6, 95% C.I. 0.4-0.8]

Table 3: Cross-tabulation of the dichotomous rugby-related concussion with loss of consciousness (Yes/No) assessed with BRAIN-Q and MSK questionnaire (MSK variable definition 2)

<b>Ever concussed with LOC (rugby-related)</b>		BRAIN-Q		Tot
		Yes	No	
MSK – main + pilot	Yes	46	7	53
	No	11	36	47
	Tot	57	43	100

Agreement = 82.0% [kappa statistic of 0.6, 95% C.I. 0.5-0.8]

Table 4: Cross-tabulation of the dichotomous any concussion (Yes/No) variable assessed with the BRAIN-Q and with MSK questionnaire

<b>Ever concussed (any)</b>		BRAIN-Q		Tot
		Yes	No	
MSK – main only	Yes	51	2	53
	No	6	8	14
	Tot	57	10	67

Agreement = 88.1% [kappa statistic of 0.6, 95% C.I. 0.4-0.9]

Table 5: The Total Number of Rugby and Non-Rugby related concussions reported through BRAIN-Q (initial assessment) and tBRAIN Recall (follow-up phone call)

Participant	BRAIN-Q			tBRAIN-Q Recall			Difference in Total Number of Concussions
	Rugby-related concussions	Non-ruby related concussions	Total number of concussions	Rugby-related concussions	Non-rugby related concussions	Total Number of concussions	
A	1	1	2	1	1	2	0
B	2	1	3	2	1	3	0
C	2	0	2	2	0	2	0
D	1	0	1	2	0	2	1
E	3	0	3	3	0	3	0
F	1	0	1	1	0	1	0
G	2	0	2	2	1	3	1
I	1	0	1	1	0	1	0
J	9	1	10	9	0	9	1
Concordance statistic, rugby-related concussions: 0.990 (0.975, 1.004)							
Concordance statistic non-rugby related concussions: 0.5 (-0.056, 1.056)							
Concordance statistic total number of concussions:0.973 (0.943, 1.003)							

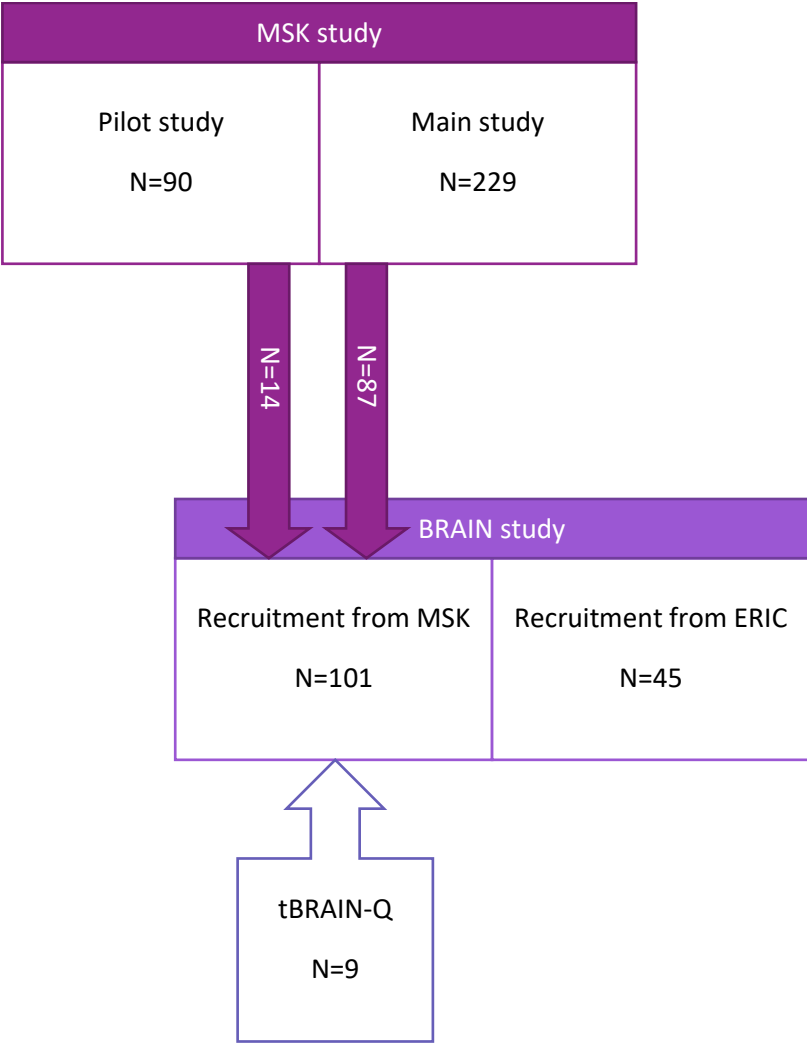


Figure 1: Flowchart depicting the sample for this study. 14 out of 90 participant assessed within the pilot MSK and 87 of the 229 assessed within the main MSK Study who were also recruited in the BRAIN Study formed the sample of the present study. Out of the 101 BRAIN participants, 9 were reassessed with the tBRAIN-Q

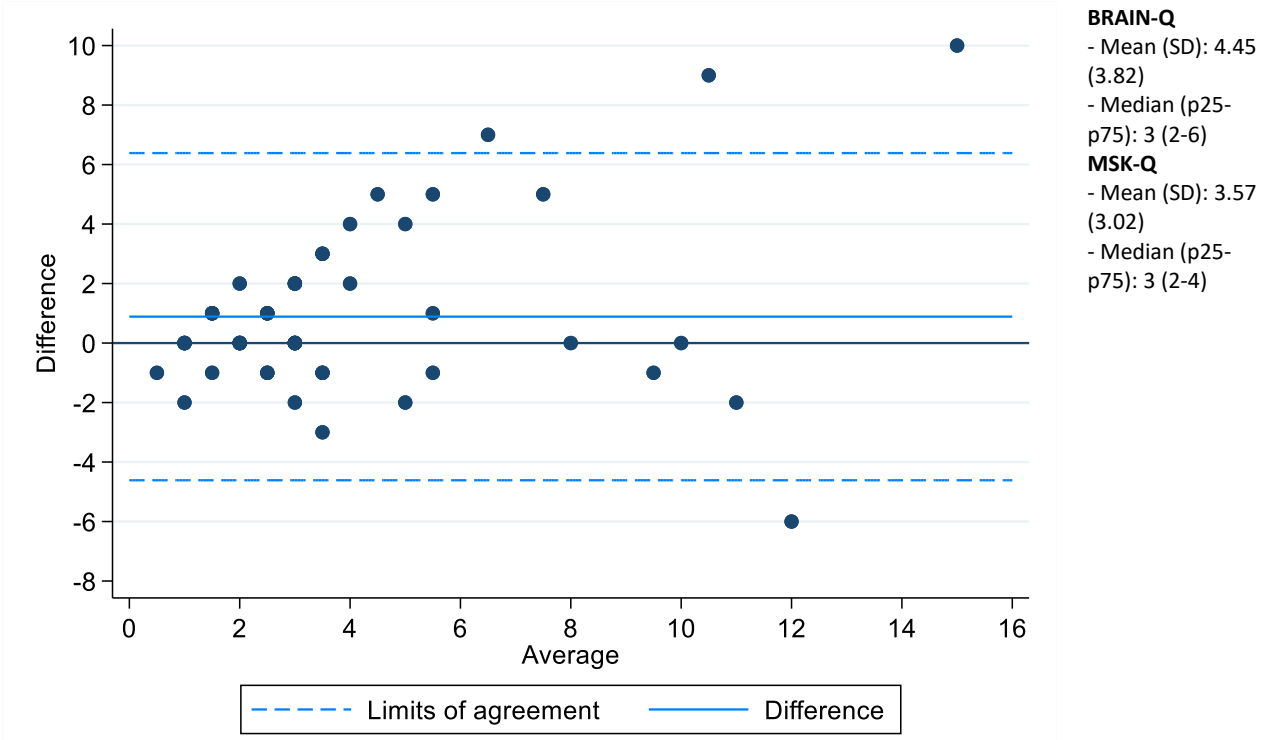


Figure 2: Bland Altman Plot – y-axis shows difference between the two concussion measures (BRAIN-Q and MSK-main) and x-axis shows average number of any concussion among 53 participants.