

SUPPLEMENTARY FILE 8

Interacting Group Process – Delphi exercise domain 1 to 4. Mixed stakeholder group online Zoom meeting: 22 September 2021

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Agenda



Young Athlete's Hip Research (YAHiR) Collaboration

Towards an international agreement on primary cam morphology research to increase value and reduce waste

#OxfordHip2021

Overall Objectives

The purpose of this consensus is to:

- ascertain level of agreement between experts on taxonomy, terminology, and definitions for primary cam morphology (including imaging outcome measures for research on primary cam morphology)
- work towards agreement on a set of research priorities on conditions affecting the young person's hip (focussing on primary cam morphology and its consequences in athletes)

VERSION: September 2021 (2)

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WEBINAR 10 - WEBINAR REGISTRATION LINK:

https://medsci.zoom.us/webinar/register/WN_m2UedGjiRUuVb5oPJtagRw

22 September consensus discussion - Zoom meeting link:

<https://medsci.zoom.us/j/92697337840?pwd=WEEdMY2pOUkdEZG54M1h3VXhkWDk2UT09>

WEBINAR 11 – WEBINAR 11 REGISTRATION LINK:

https://medsci.zoom.us/webinar/register/WN_mdKVnM7rReaQg-M1QzjSrA

23 September consensus discussion - Zoom meeting link:

<https://medsci.zoom.us/j/97928325865?pwd=S2RNV3N6RHIDa3ZLQkZ5VU45ZDIJQT09>

Objectives – To:	Type of consensus meeting	Date
1. ascertain level of agreement between experts on taxonomy, terminology, and definitions for primary cam morphology (including imaging outcome measures for research on primary cam morphology)	Virtual consensus meeting (Zoom)	22 September 2021 12-4pm BST
2. work towards agreement on a set of research priorities on conditions affecting the young person's hip (focussing on primary cam morphology and its consequences in athletes)	Virtual consensus meeting (Zoom)	23 September 2021 12-4.30pm BST

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Wednesday 22 September 2021 - Online (Zoom)		
Webinar 10: Sharing results of the YAHiR Collaboration's Delphi exercise on primary cam morphology terminology, definitions, and imaging outcome measures		
WEBINAR REGISTRATION LINK: https://medsci.zoom.us/webinar/register/WN_m2UedGjjRUuVb5oPJtagRw		
Faculty: Clare Ardern, Paul Dijkstra, Eugene McNally, Siôn Glyn-Jones, Joanne Kemp		
Objectives Following this session participants will be able to: <ol style="list-style-type: none"> 1. Apply a standard taxonomy, terminology, and definition for primary cam morphology and femoroacetabular syndrome 2. Discuss the consensus on imaging outcomes for studies on how primary cam morphology develops 3. Consider the benefits to stakeholders of applying consistent terminology and definitions for primary cam morphology 		
12.00	Introduction - Delphi study on primary cam morphology	Paul Dijkstra, Clare Ardern and Joanne Kemp
12.10	Consensus definition for primary cam morphology – results of the Delphi Study	Paul Dijkstra
12.25	Consensus taxonomy and terminology for primary cam morphology and femoroacetabular impingement syndrome	Clare Ardern
12.40	Consensus on imaging outcomes for studies on how primary cam morphology develops	Eugene McNally
13.00	Panel discussion	All with Siôn Glyn-Jones
13.30 Tea break (end of Webinar 10)		
Online mixed stakeholder group discussion and feedback		
Zoom meeting link: https://medsci.zoom.us/j/92697337840?pwd=WEEdMY2pOUkdEZG54M1h3VXhkWDk2UT09		
14.00	Consensus group refining discussion: 4-6 groups of 6-8 individuals representing each of the 6 Delphi Study stakeholder groups) <i>Discussion: Delphi exercise domain 1-4 results and areas of tension and dissent</i>	Chairs: Paul Dijkstra, Clare Ardern and Karim Khan Stakeholder group leads: Group 1: Andrea Mosler & Amy Price Group 2: Joanne Kemp & Sion Glyn-Jones Group 3: Karim Khan & Dawn Richards Group 4: Sean McAuliffe & Eugene McNally Group 5: Paul Blazey & Rich Willy Group 6: Andreas Serner & Mike Clarke
15.00	Feedback: 5 min per group Summary, closing remarks and next steps	Paul Dijkstra, Clare Ardern and Karim Khan

Discussion topics

Primary Cam Morphology (PCM)

Definition

- Despite strong consensus on the importance of **PCM as a concept**, some panelists are not convinced
- PCM is more common in **asymptomatic males**. Yes, but we **need more research in female cohorts**
- PCM often **occurs in both hips** (unlike secondary cam morphology)
- PCM also includes cam morphology of unknown origin (cause). Consider role of **genetics**
- PCM likely develops during skeletal maturation in young adolescents (with no current or previous hip disease), as a **normal physiological response due to high-load sporting activity** and other unconfirmed risk factors

Terminology

- Let's validate the patient. It's a **morphology** (not: "lesion", "deformity", "abnormality")
- Is **'bump'** patient/athlete friendly language? What about 'prominence'?
- Let's validate the patient. It's **FAI Syndrome** (not: 'symptomatic FAI', 'cam-type', 'FAI cam FAI')

Taxonomy

- Is it difficult to distinguish between PCM and secondary cam morphology in **patients** with femoroacetabular impingement syndrome?

Imaging Outcomes

- What is the ideal time interval for **serial imaging** (MR imaging) in **studies** on PCM **aetiology**? Early adolescent cohorts (9 to 16y)
- MR imaging vs radiographs (AP and lateral) for **long-term prospective studies** on PCM (and FAI syndrome) prognosis (likely decades)

Results

Definitions – Delphi domain 1

Box 1 Interacting Group Process: mixed stakeholder group Definition domain discussion topics and results

Topic 1 – Primary cam morphology as a concept: Despite strong consensus on the importance of primary cam morphology as a concept, some panellists are not convinced

The Delphi panel, and mixed stakeholder groups, agreed on the importance of primary cam morphology as a concept. This taxonomy, differentiating between primary and secondary cam morphology, offers a number of advantages that offset its drawbacks—*‘their origins are important to distinguish’*, and *‘it has utility in research, prognosis, and treatment’*. In research the taxonomy is *‘important for classification’*, while the prognosis is often worse for secondary cam morphology. Treatment maybe distinctly different as the majority of individuals with primary cam morphology will never present with any symptoms. The panel contended more work is needed to authentically engage a small group that is not yet convinced that *primary* cam morphology is an important concept.

Topic 2 – Prevalence of primary cam morphology in males vs females: Primary cam morphology is more common in asymptomatic males. Yes, but we need more research in female cohorts.

Although there is agreement, albeit *‘based on the (limited) available literature’*, that primary cam morphology is more common in males and mostly asymptomatic, it is important to note that female athletes also develop this morphology and that *‘longer term consequences of PCM seem to affect women as much as men.’* More inclusive research is needed involving minoritised female cohorts.

Topic 3 – Primary cam morphology often occurs in both hips: Primary cam morphology often occurs in both hips (unlike secondary cam morphology)

Although there is agreement that primary cam morphology, unlike secondary cam morphology, often occurs bilaterally, and this distinction *‘is the defining element for PCM vs SCM, and important for patients’*, this is not always the case. Some patients might have unilateral primary cam morphology while others might present with a combination of primary- and secondary cam morphology.

Topic 4 – Primary cam morphology’s unknown origin and the role of genetics: Primary cam morphology also includes cam morphology of unknown origin (cause). Consider role of genetics

The mixed stakeholder groups agreed that primary cam morphology also include the group where no clear aetiology *‘at an individual level’* exists. It is likely that a *‘complex relationship’* between primary cam morphology and *‘a genetic susceptibility’* exists. Genetics as risk factor, and *‘the*

interplay between genetic risk and load relationship’ should therefore be considered and researched.

Topic 5 – Primary cam morphology develops as a normal physiological response to load:

Primary cam morphology likely develops during skeletal maturation in young adolescents (with no current or previous hip disease), as a normal physiological response due to high-load sporting activity and other unconfirmed risk factors

Despite strong consensus that primary cam morphology develops during skeletal maturation “as a normal physiological response to load” (Statement 1) further qualified as “high-load sporting activity” (Statement 11), some panellists, during the online discussions, felt “normal” is *‘potentially problematic’*. However, the high prevalence of primary cam morphology in largely asymptomatic professional athletes—*‘several studies showed >80% prevalence’*—begs the question: *‘when does it [physiological response] become abnormal? ...when it’s very painful?’* Furthermore, high-load sporting activity for one athlete might be normal-load sporting activity for another; load type (*‘torsion, varus/valgus’*) and *skeletal maturation* status are both important variables to consider in clinical practice and research.

Terminology – Delphi domain 2

<p>Box 2 Interacting Group Process: Mixed stakeholder group terminology domain discussion topics and results</p>
<p>Topic 1 – Morphology: Let's validate the patient. It's a morphology (not: 'lesion', 'deformity', 'abnormality')</p>
<p>The Delphi panel achieved strong consensus on using the term “morphology” and to abandon “lesion”, “deformity” and “abnormality”: <i>'large foreign words set the tone for fear, unknown, not in control, especially about [the] outcome.'</i> Although the majority agreed, some felt that <i>'language didn't necessarily change things for patients'</i>, and that the consequences (<i>'the pathology part'</i>) of primary cam morphology <i>'is the bigger problem and needs to be part of the file, but the patient doesn't necessarily need to know about this [wording]'</i>. Others thought that <i>'morphology should be avoided in patient consultations as it's unfriendly, not well understood and likely medical "jargon"'</i>. A further problem is that “morphology” doesn't always translate well into other languages.</p>
<p>Topic 2 – “Bump” or “prominence”: Is 'bump' patient/athlete friendly language? What about 'prominence'?</p>
<p>Although “bump” is easy for patients to understand and visualise (<i>'I use “bump” to make it easy for patients'</i>), some felt primary cam morphology is <i>'likely more complex than “bump”'</i>. <i>Morphology and syndrome sound more scientific. Bump totally not'</i>. Another group warned about the possible <i>'nociceptive response in patients'</i> caused by associating the term “bump” with <i>'bumping bones'</i>, or of <i>'things hitting'</i>. <i>Therefore we may need to take care with using this term [bump] too.'</i> One mixed stakeholder group concluded that the <i>'language we use in patient-facing consultations should be tailored to the person'</i> and mentioned alternatives like <i>'bumpy-shape'</i> and <i>'egg-shape'</i>. There was agreement to use <i>'less threatening'</i> language supported by visual aids <i>'images/figures'</i>. While it might be appropriate to <i>'tailor terms to three different target audiences: researchers, clinicians and patients and public'</i>, stakeholder groups suggested that Patient and Public Involvement group should inform further research on this.</p>
<p>Topic 3 – FAI syndrome: Let's validate the patient. It's FAI syndrome (not: 'symptomatic FAI', 'cam-type FAI' or 'cam FAI').</p>
<p>Validating the Warwick Agreement, the Delphi panel achieved strong consensus on using the <i>'much preferred scientifically'</i> term, “Femoroacetabular Impingement (FAI) Syndrome” for FAI in patients with symptoms (pain/stiffness etc). However, some felt that “syndrome” sounds <i>'too serious'</i>. Arguing that <i>'words matter'</i> panellists discussed the importance to <i>'tailor language to the individual'</i> and distinguish between a <i>'research discussion vs talking with patients'</i>. Commenting on the 2016 Warwick Agreement, a member of that panel mentioned <i>'we considered whether 'syndrome' might apply a negative label to patients, but the expert patient member of the panel did not feel this would be the case, but could be good to bounce this of more patients too.'</i> We therefore need <i>'further patient-orientated research to assess whether it [syndrome] has negative consequences and whether femoroacetabular impingement (FAI) used in isolation may be a better term when communicating with patients'</i>.</p>

Taxonomy – Delphi domain 3

Box 3 Interacting Group Process: Mixed stakeholder group taxonomy domain discussion topics and results

Topic 1 – Distinguishing between primary- and secondary cam morphology in patients with FAI syndrome (Statement 34): Is it difficult to distinguish between primary cam morphology and secondary cam morphology in patients with femoroacetabular impingement syndrome?

The general agreement was that it is important (and not necessarily difficult) to distinguish between primary and secondary cam morphology in clinical practice and in research: *‘Where we can, we should make the differential diagnosis as it affects the prognosis and therefore the management of the problem’*. A librarian panellist emphasised the benefit of *‘consistent terminology’* when reviewing the literature: *‘using primary vs secondary allowed searching the literature more clear’*.

Although most panellists felt that *‘history is key’* to distinguish between primary and secondary cam morphology, others felt that *‘obtaining a detailed history and discussion with patient is more important than a label of primary and secondary’*.

It can be clinically challenging when a combination of primary and secondary cam morphology exists in the same patient as *‘there are some cases where primary cam morphology exists prior to a secondary injury (e.g. SCE), and these cases can be a little more difficult to diagnose but are less commonly observed’*.

A small number of panellists felt that *‘the inclusion of “primary” in the term in the Delphi [statements] influenced responses to the specific questions in the Delphi rounds’*. Some were not convinced that “secondary cam morphology” exists: *‘There is no secondary CAM, it is another diagnosis. Secondary CAM is in a different position than primary cam and looks different (on radiology and in arthroscopy) and should not be considered CAM’*.

One panellist commented that *‘primary and secondary is a causal statement’* and that *‘the terms are not necessary, but they are not a problem either’*. Another was concerned that a disease taxonomy is used for an asymptomatic morphology: *‘The differentiation of primary and secondary CAM morphology is not related to current symptoms or disease, but because it is taken from disease taxonomy, it may sound like a disease, thus using the terms primary or secondary CAM morphology might make a CAM finding in an asymptomatic person seem to be a more serious negative issue.’*

Imaging outcomes – Delphi domain 4

Box 4 Interacting Group Process: Mixed stakeholder group imaging outcomes domain discussion topics and results**Topic 1 – Time interval for serial imaging in studies on primary cam morphology**

aetiology: What is the ideal time interval for serial imaging (MR imaging) in studies on primary cam morphology aetiology? Early adolescent cohorts (9 to 16y)

While commenting on the *'obvious ethical consideration for the amount or frequency of imaging'*, a radiologist in one of the mixed stakeholder groups felt *'the more the better in terms of insight'*, and also raised the possible benefit of radial vs block imaging – *'block images may allow you to evaluate the images later through the use of novel techniques such as AI [artificial intelligence]'*.

While one group felt that yearly MR imaging is appropriate when investigating how primary cam morphology develops in boys (from 11 to 16 years) and girls (from 9 to 14 years), another commented that *'the time interval should be much shorter if it is to be truly 'ideal' (e.g. every 3 months). This would capture periods of considerably faster growth or considerable changes in load'*, while *'more frequent imaging will help in periods of rapid growth but it is also important to have frequent serial imaging even in periods without rapid growth to assess the influence of growth spurts.'* However, one panellist questioned the value of serial imaging as, for example, *'positions [of primary cam morphology] might vary making it impossible to use them to track changes over time'*. One group felt that the use of serial radiographs to investigate primary cam morphology aetiology constitutes research waste: *'if you can't do serial MRIs at short enough intervals, don't waste time and money, don't do the study.'*

Topic 2 – MR imaging vs radiographs for long-term prognosis studies: MR imaging vs radiographs (AP and lateral) for long-term prospective studies on primary cam morphology (and FAI syndrome) prognosis (likely decades)

MR imaging trumps radiography and *'should be the investigation of choice where at all possible in adolescent populations'*. The quality of imaging is better, it better quantifies cartilaginous progression in adolescents where *'the use of alpha-angle on x-ray can be misleading and therefore inaccurate'*, and, as it does not pose a (cumulative) radiation risk *'ethics committees are more likely to accept MRI based studies'*. One panellist commented on the possible benefit of low dose 2D/3D imaging that *'may reduce the barrier to x-rays with improved 3D modelling and reduced radiation'*.

However there are at least 3 issues with MR imaging: cost, availability (equipment and expert radiologists), and the burden of procedure (time, claustrophobia etc). MR imaging is challenging in young adolescents *'due to difficulty remaining still, i.e. movement artefact'*.

The group agreed that further work is needed to develop and refine consensus on the specific and standardised imaging protocol: *'If x-rays are utilised then it has to be reinforced on the views that are valuable and this message should be repeated in order to support this becoming routine practice; not all facilities are skilled with specific radiograph images e.g., Dunn'*.

It is further important to consider dissemination of findings: *‘Do athletes want to know the results? How, what, and when do we communicate imaging results to participants or parents? Do we consider positive/negative response by athletes/parents, and provide them with the “opt in” opportunity not to be informed of their individual imaging results?’* Group members raised four important points from the athlete/parent’s perspective. First, parents *‘were not comfortable’* with cumulative radiation exposure associated with serial radiographs. Radiation exposure is an *‘ethical dilemma in this area’* with *‘a need to be up front and transparent with information so parents are aware’*. Second, sharing of imaging results is a *‘hugely important area’* and research teams should carefully consider the possibility that *‘parents may pick up the information or interpret it differently than health care practitioners’*. Third, research teams should consider *‘an “opt in” option for participants and parents where, except if there is an issue with an imaging finding, they will not be informed of the results’*. Last, research teams should carefully consider how they communicate periodic imaging results and suggested a *‘common approach to dissemination of results/imaging is needed’*.