

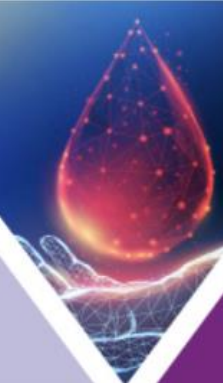


 **EAHAD**
European Association for Haemophilia
and Allied Disorders

2024

FRANKFURT GERMANY

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17th ANNUAL CONGRESS
OF THE EUROPEAN ASSOCIATION
FOR HAEMOPHILIA AND ALLIED DISORDERS

Exploring Posttraumatic Stress Symptoms and Pain Memories in People with Haemophilia and the influence on current pain experience

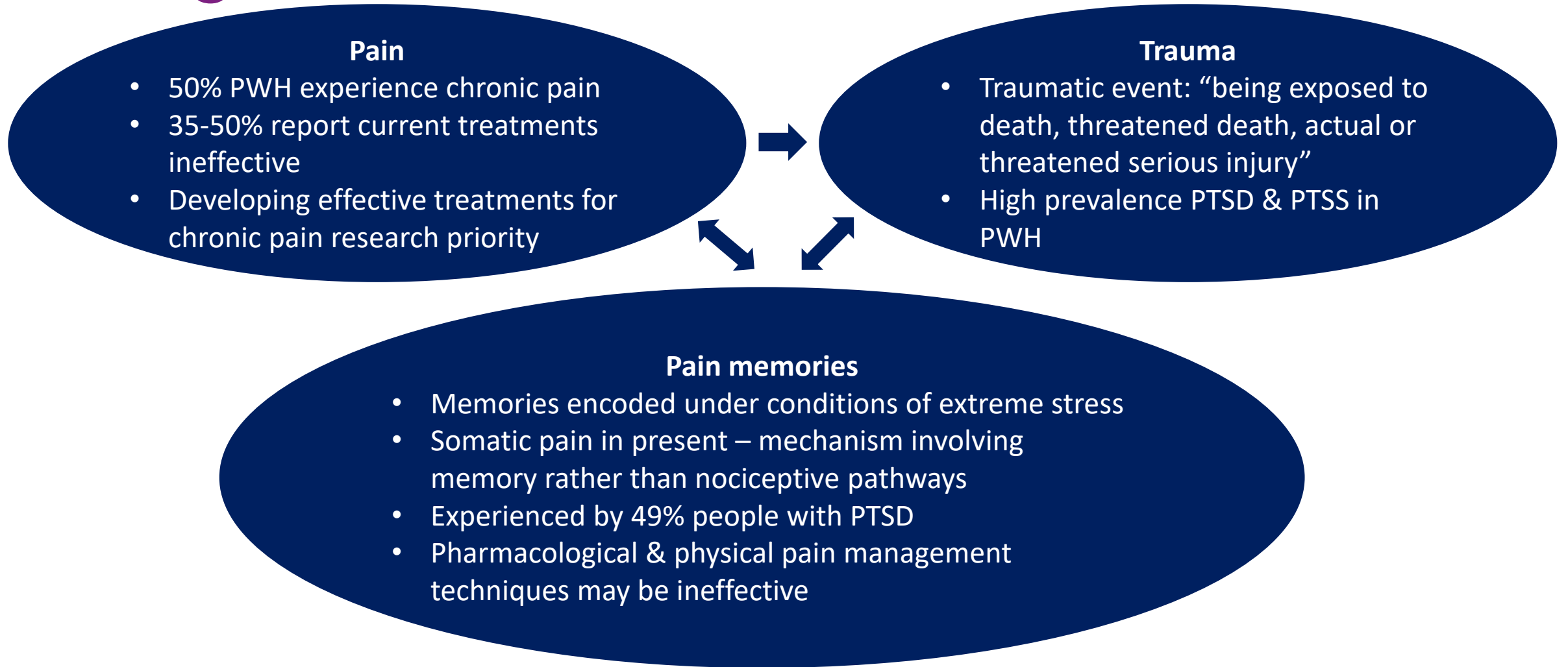
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Disclosure for Anna Wells

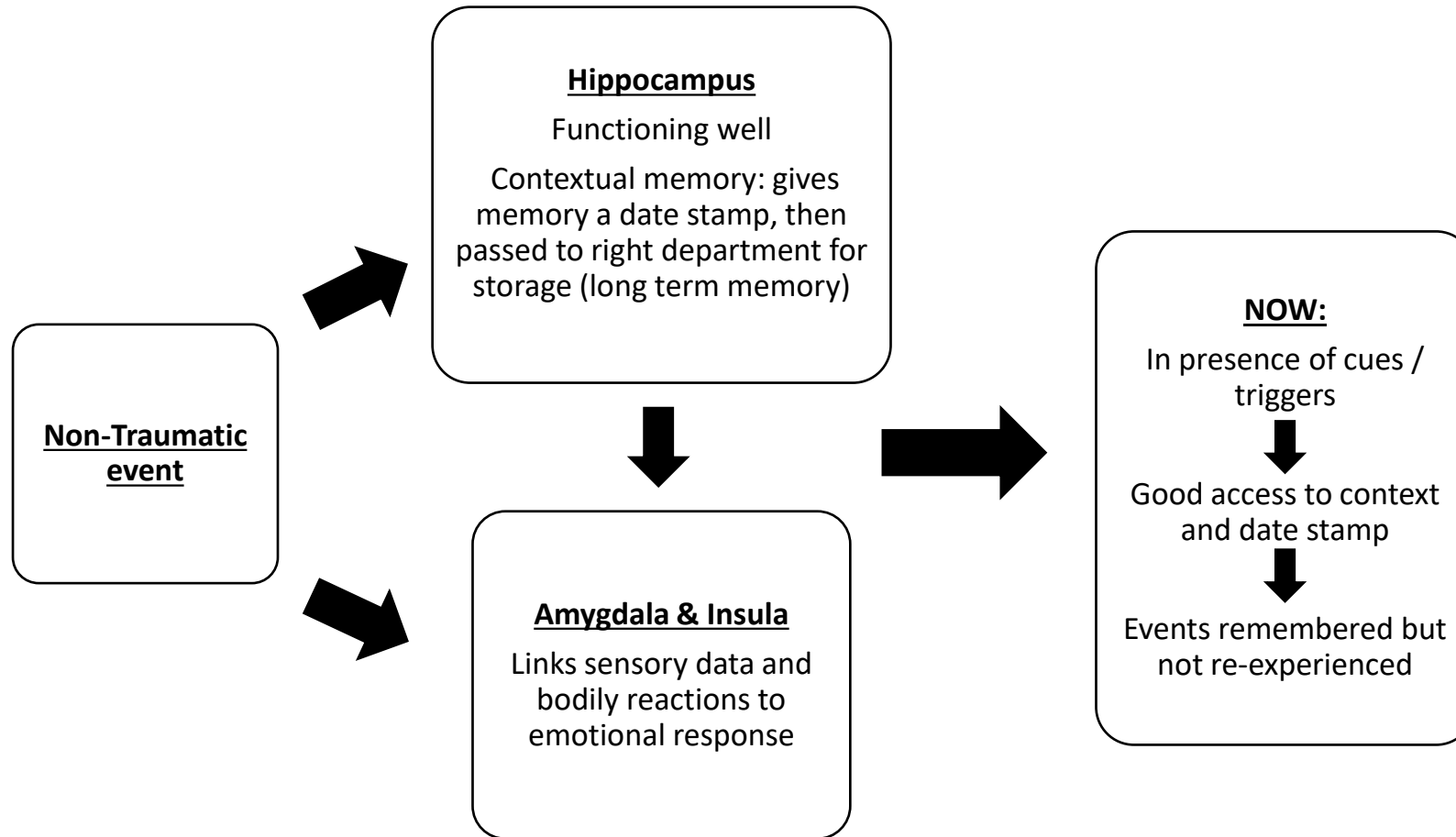
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Background



McLaughlin et al. (2020); James Lind Alliance (2018); American Psychiatric Association (2013); Stahl et al. (2023); Macdonald et al. (2018)

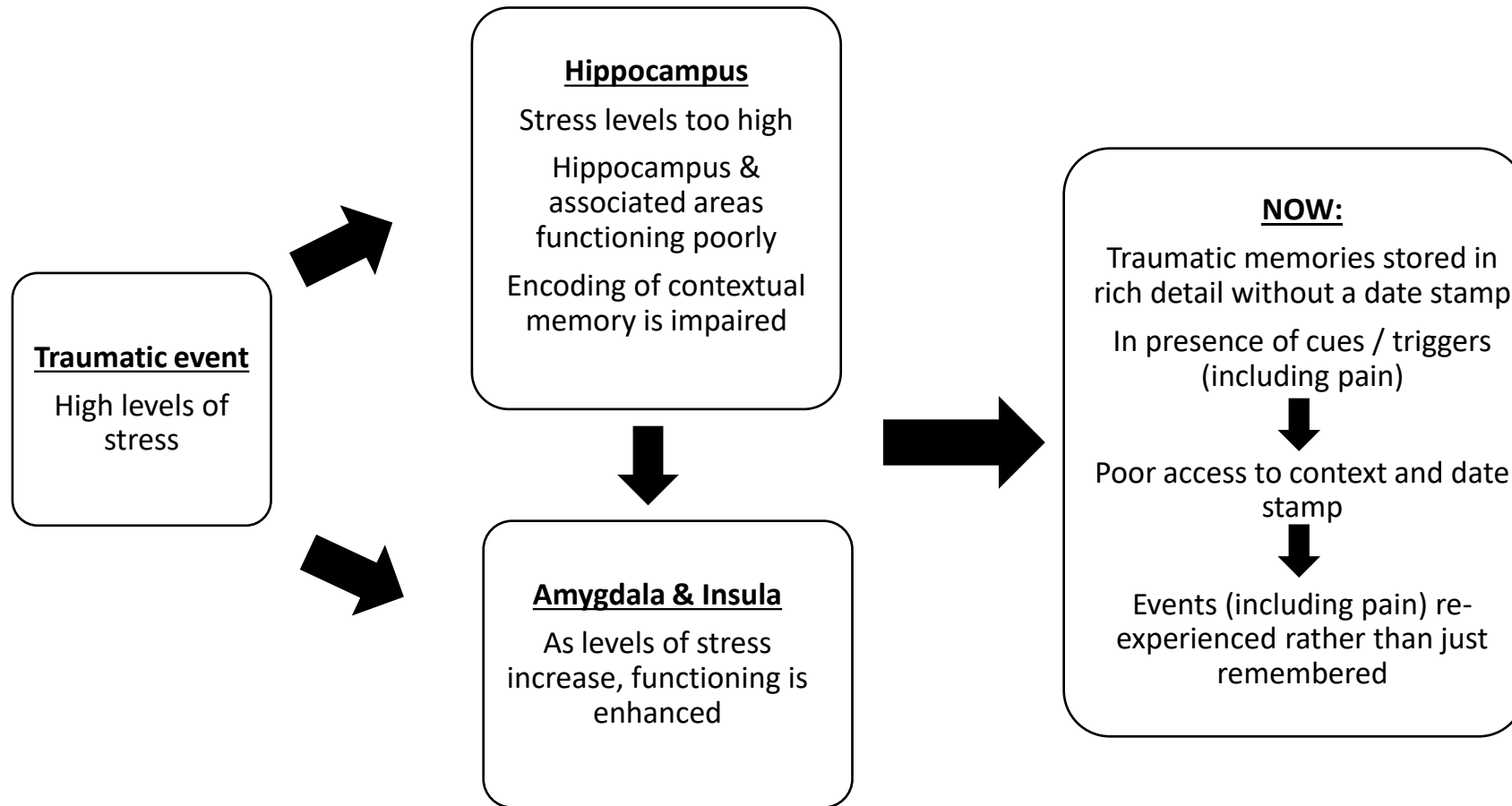
Background



Processing of non-traumatic memories

Wells et al. (2021)

Background



Processing of traumatic memories: the experience of pain memories

Wells et al. (2021)

Methodology

PWH

- 14 semi-structured interviews Nov'22–Jan'23
- Participants aged 21-71 (mean 41.5)
- Data analysis: multi-perspective thematic analysis

HCP

- 12 semi-structured interviews Dec'23-ongoing
- Medical, Nursing, Physiotherapy, Psychology
- Data analysis: multi-perspective thematic analysis

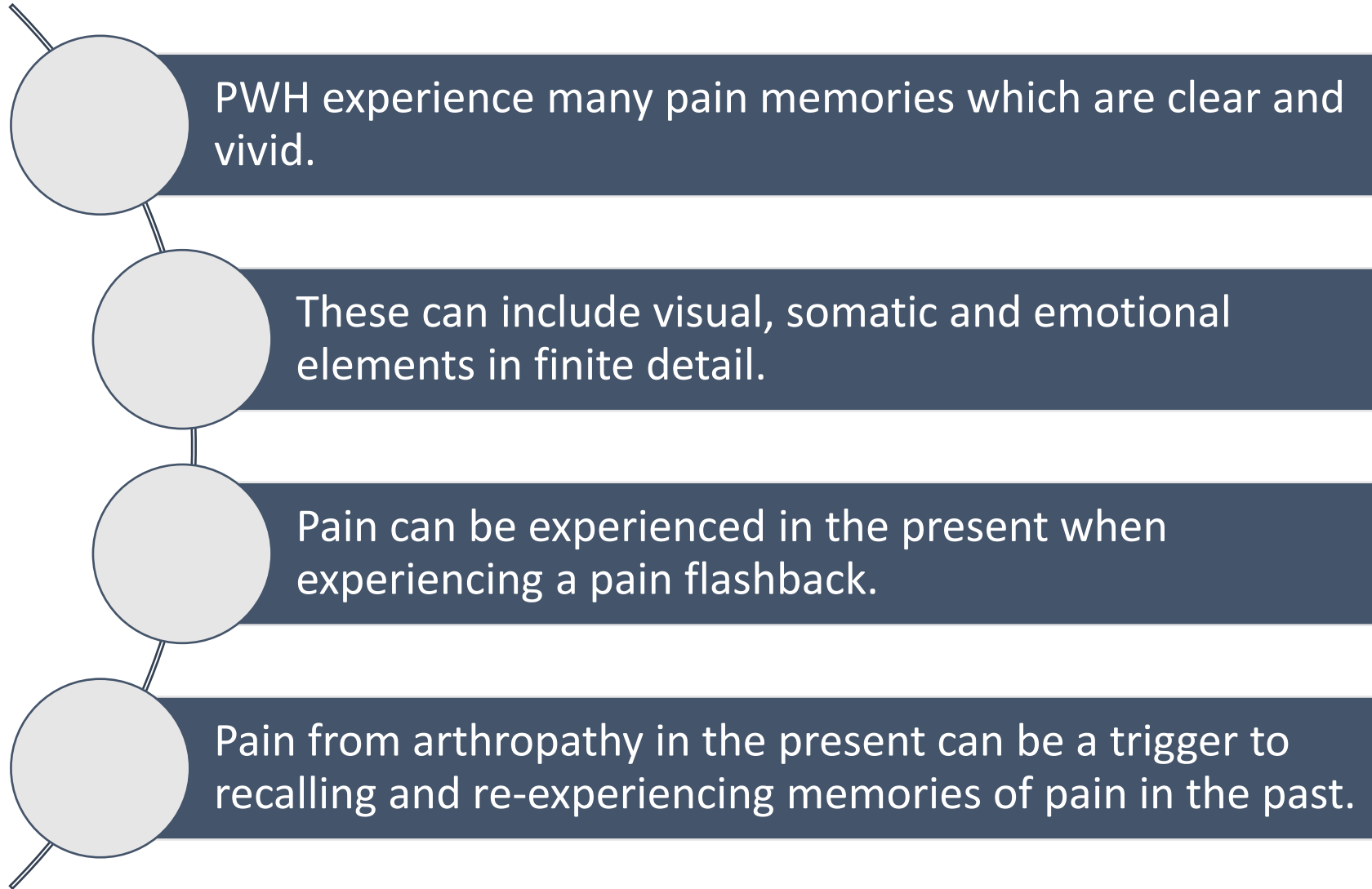
Results: PWH

“And what that pain memory brings is flashbacks, weirdly ... I can remember exactly where I was and it’s a weird thing that your brain does but I can see and feel the pain. I can feel it.”

“Pain is just one part of that spectrum of trauma, and is no different, in the sense that the memories are retrievable so immediately that, it's as if it was yesterday.”

“If I think about the bleed, there's no physical pain, but I can sense the mental pain and that the memory comes back of that pain”

Results: PWH



Results: PWH

“We kind of build this little, put 4 walls around us, and no one comes in. And this was like, up until a few years ago, (how) I dealt with pain.”

“This is the first time I’ve spoken about this.”

“You talk about stuff that happened with other people who have been through it and decompression is the best way of solving that future PTSD.”

Results: HCP

“The whole team have got to be alert ... It’s giving people the opportunity to start that conversation, even if you yourself perhaps don’t have all the skills needed to help.”

“I wonder if we as professionals haven’t quite gone back and begun to properly re-evaluate people’s normal responses to things that happen to them.”

“Chronic pain is just such a difficult thing to get your head round, and it’s difficult for clinicians ... To somebody understanding that whose entire life has been it hurts when I bleed, and that’s what the problem is. It’s a very very difficult concept to get your head round.”

Implications for Practice

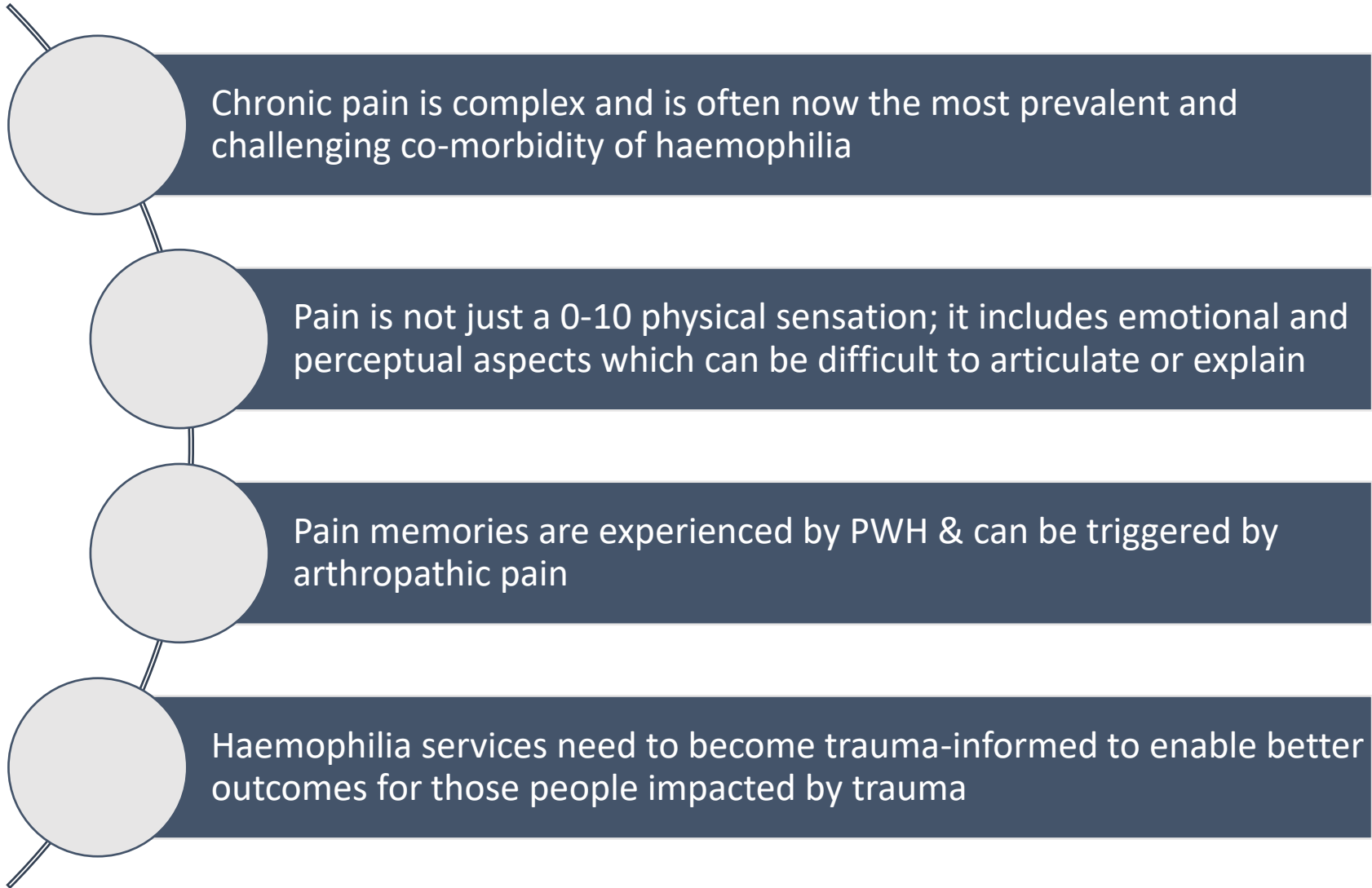
Pain is multifaceted and may have a memory element influencing the pain experience for some PWH

Pain science is complex, difficult for clinicians to explain & it may be hard for patients who have an engrained belief that pain = bleed

Psychological trauma affects many PWH. Clinicians need to become trauma-informed to enable recognition signs & sx, and to prevent re-traumatisation with ongoing interaction with our services

We need to consider how we can offer a safe space for PWH to discuss both pain and trauma, and look at wider peer to peer support opportunities

Conclusions



Thank you

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Dr Sarah Whitaker



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