



Transforming the Real Experience of UK Armed Forces Veterans Living with Chronic Pain

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Umio research and recommendations | November 2023

# **Executive summary**

This report presents Umio's qualitative research into UK armed forces veteran experiences with chronic pain. Undertaken in March-April 2023, it is one deliverable from our 12-month project with the UK Office for Veterans' Affairs (OVA) in the Cabinet Office. This was supported with a grant from their Health Innovation Fund, and facilitated by the Defence and Security Accelerator in the Ministry of Defence.

Based on our research, we estimate that 45% or 1 million of the current 2.3 million UK veterans experience chronic pain. Of those with chronic pain, we further estimate that 35% / 350k regularly experience moderate or severe persistent pain, the majority of which are of musculoskeletal origins. The overall prevalence estimate is slightly higher than the 45% figure we reported previously in our initial proposal. Further, based on our research, we believe there are differences in prevalence depending on which force a veteran served in. Those serving in the British Army are likely to have higher prevalence of chronic pain, possibly as high as 65%.

We estimate too that for UK veterans with chronic pain, approximately **15% or 147,000** also suffer with PTSD.

The dominant clinical biomedical model of pain assessment, diagnosis and treatment used in the NHS can work for some veterans with musculoskeletal injuries but for many others, it does not. Using Umio real experience thinking, models and concepts, the report emphasizes the need to adopt a more holistic approach to understanding and finding ways to address veteran chronic pain. This perspective argues that pain has impacts and meaning in wider veteran experience and there is no experience of pain without its affective component. Pain is not solely a sensation from injury to the body but the affects arising from its impact in the veteran sufferer's wider values, encounters and interactions in the world.

Using this perspective, the report introduces three Umio research and design concepts to shape the enquiry into veteran pain experiences reported in the study. Using these concepts – a new holistic interactional model of veteran real experience, expansive wellbeing creation as scope and purpose, and assemblages thinking – the report explains how we can use them to improve how we see and know how and why veteran chronic pain experiences originate, emerge, differentiate, persist and change over time. Such a developmental or evolutionary view supports novel systems, policy, strategy organisational and all stakeholder innovation in the lives of veterans with pain. The report explains these.

15 semi-structured, one-hour qualitative telephone interviews were undertaken with male and female veterans of mixed age and from all three service affiliations, and with present enduring experience of chronic pain. Themes explored were pain sites, pain origins, pain medication, veteran attitudes to pain linked to their "military mindset", pain knowledge, help-seeking behaviour or outlook, material-spatial impacts spanning home, transport, travel and environment, and social-cultural impacts on family, friends, isolation, work, healthcare, charities, and other veteran interactions.

A key output of the research is the production of five different veteran outlooks on their chronic pain. These translate into particular veteran pain management strategies and approaches whose limitations and consequences are explored.

The paper concludes by summarising the implications of the Umio concepts and research for veteran with pain (and veteran wellbeing more widely) OVA/government and healthcare policy, strategy and stakeholder activity and engagement. We argue that these apply to any veteran with pain population, anywhere in the world.

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## Introduction

We estimate that almost **half of current UK veterans experience chronic pain** (defined (by WHO) as pain lasting a minimum of three months).

In March and April 2023 15 in-depth one-hour qualitative interviews were undertaken with a mix (age, gender, ethnicity, location) of veterans of all UK armed forces having diverse experiences with chronic pain. All veterans interviewed experienced pain currently and suffered self-reported impacts on everyday life functioning, and on their personal values and goals.

In addition to the research findings, the report summarises the methodological and analytical concepts used by Umio to enquire into the lived (or we prefer, real) experience of veterans with chronic pain. These holistic experiential-based frames of thought and investigation (Umio background IP) can be used for any complex, chronic, multi-factorial condition. The report explains the veteran policy, strategic and other implications of using these concepts in tandem with the research findings and outputs. Together, they inform the operating principles and underpinning value-mechanisms of the forthcoming Umio experience ecosystem to be developed in prototype form as part of this contract.

The report is structured as follows. First, we summarise recent developments in chronic pain thought, assessment, diagnosis and treatment practice including the new official ICD chronic pain designations introduced by WHO in 2022. We then introduce the Umio real experience method and design concepts that align with this rethinking and reclassification. We describe the qualitative research and our key findings. Finally, we propose and briefly discuss the primary implications for veteran with pain (and veteran wellbeing more widely) OVA/government and healthcare policy, strategy and stakeholder activity and engagement. To begin, we estimate the epidemiology of chronic pain within UK veterans based on published data and our own estimates.

# **Epidemiology of chronic pain in veterans**

# Veteran population with chronic pain

Data on the number and percentage of UK veterans with chronic pain is not officially published or known exactly. The National Health Service (NHS) does not record the health status of veterans, making it hard to know with much precision the extent of UK veteran pain experience (Gauntlett-Gilbert & Wilson, 2013). However, based on a handful of US and Canadian veteran research papers, we can estimate that about half of all UK veterans regularly experience some type of chronic, persistent pain (Adams et al., 2021; Van Den Kerkhof et al., 2015). In the latter study of Canadian Armed Forces veterans, the point prevalence of chronic pain was 41%. A very recent US research paper (Vowles, Schmidt and Ford, 2022) found that chronic pain is one of the most common reasons for treatment seeking among veterans within the US Veterans Health Administration (VA). It states that **up to 68**% of US veterans experience a chronic pain condition.

Due to the physically strenuous nature of their training and operational activities, military personnel are at a much higher risk of developing chronic pain compared with civilians. Those in the army or infantry are at an increased risk of suffering injuries affecting their back and legs, especially the knees, lower legs and feet. This is due to training on hard surfaces, marching, carrying heavy equipment, and assuming specific positions. Six out of ten medical discharges from the British Army were due to musculoskeletal issues (Gauntlett-Gilbert & Wilson, 2013). Personnel in the RAF and Royal Navy tend to be more at risk of back, neck and shoulder injuries due to repeated lifting and moving of heavy equipment and machinery, and from restricted movements in confined spaces. As we explore in our research, everyday impact, lifting, carrying and movement-based injuries in service roles frequently have debilitating consequences that worsen over time.

With widespread risk of exposure to trauma and stressors in operational activities, veterans are also more susceptible to developing posttraumatic stress disorder (PTSD). Thompson et al. (2011) found that PTSD is present in 11% of veterans surveyed (compared with 2.4% of the Canadian population). In another Canadian study¹ (van den Kerkhof et al., 2015), 93% of veterans with PTSD were found to also have chronic pain indicating the common co-morbidity of the two conditions.

These studies demonstrate the mutually reinforcing effects of comorbid PTSD, depression, anxiety and chronic pain on personal functioning, mood and outlook with all leading to cumulative negative impacts including withdrawal and social isolation. Such common incidence of co-morbid pain and mental health problems in veterans demands a holistic mode of assessment and treatment.

# Estimates of prevalence of chronic pain and PTSD in UK veterans

Based on the above studies and the reports of veterans interviewed in our research, we estimate that **45%** or **0.98 million of the current 2.3 million UK veterans experience chronic pain** (Figure 1). Of those with chronic pain, we further estimate that **35%** / **350k** regularly experience moderate or severe persistent pain, the majority of which suffer from musculoskeletal pain problems as documented above. Further, based on our research, we believe there are differences in prevalence depending on which force a veteran

<sup>&</sup>lt;sup>1</sup> Canada conducted regular telephone and internet "Life after Service" surveys of military personnel transitioning into civilian life. <a href="https://www.veterans.gc.ca/eng/about-vac/research/research-directorate/publications/reports/survey-transition-civilian-life">https://www.veterans.gc.ca/eng/about-vac/research/research-directorate/publications/reports/survey-transition-civilian-life</a>

served in. Those serving in the British Army are likely to have higher prevalence of chronic pain, possibly as high as 65%.

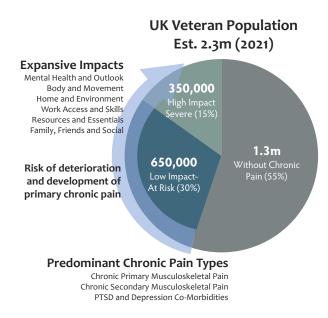


Figure 1: Umio estimates of prevalence of chronic pain in veterans in the United Kingdom

We estimate too that for veterans with chronic pain, approximately **15% or 147,000** also suffer with PTSD. As we report in our research findings below, pain – especially when co-morbid with PTSD - negatively impacts whole veteran lived experience and all with pain are at risk of developing further disability and impairment. In fact, the affective, material and social consequences of having chronic pain can become more isolating and dislocating than the pain itself over time. Fatigue from sleeplessness can lead to a loss of employment and reduced work potential, withdrawal from social circles results in loneliness, and lack of exercise, and poor diet can lead to weight gain and cardiovascular issues.

Such expansive health and wellbeing impacts require an alternative way of seeing chronic pain as well as a method for understanding veteran's wider experiences with pain beyond a narrow and often dualistic physical (biomedical/biological/bodily) and mental (psychological/mind) health perspective.

Fortunately, emergent pain thinking is developing such a more holistic, integrative and experiential approach in chronic pain assessment, diagnosis and treatment practice. Next, we describe this shift.

# **Emergent thinking in chronic pain practice**

# The dominant chronic pain model

For decades, the dominant mode of thought in chronic pain practice has been clinical, biomedical and objectively diagnostic focused on observable symptoms, pain sites and pathologies (for a general review, see Boddice, 2017 for a short introduction). This is based on the common-sense view of pain as a sensation arising directly from an injury or damage to tissue, bone or the nerve systems or endings in a part of the body. An injured nerve sends a signal to the brain (via the spinal column) which then determines a series of reactions to the pain. With a focus on the bodily site that is injured or damaged, pain itself becomes secondary to the source of the pain – the injury or trauma itself. Assessment and diagnostics then follow an objective, clinical evaluation linked to causal factors and mechanisms located at the injury site, often quantified using an intensity- or magnitude-based model of pain sensation.

This dominant clinical mode of thought inevitably leads to a medication (to control or regulate the pain intensity), surgery (to fix, repair or reshape the bone or tissue damage at the injury site) and physiotherapy (to restore motor and muscle strength and function) treatment model. It uses a functional physiological model aimed at restoring motor movement and physical capacities. By and large, this is the model used in the military by medical personnel when in service too.

# Towards a new holistic model of chronic pain

A clinical biomedical model of pain assessment, diagnosis and treatment can work for some veterans but for many others, it does not. There are three reasons why:

- Chronic pain can arise independently of a single bodily or neuronal injury or damage. It can be non-specific or centralized within the body, and felt in different locations in unpredictable ways.
- The affects of pain arising from a bodily injury or damage can become more debilitating over time and develop into a wider pain chronicity, largely due to the failure of the biomedical mode of treatment intervention
- Pain has impacts and meaning in wider experience. There is no experience of pain without its affective component. Pain is not solely a sensation from an injury to the body but the affects arising from its impact in the sufferer's wider encounters and interactions in the world.

In the latter sense, pain is no longer seen as just the result of a damaged bodily mechanism forming a sensation but rather becomes something to mean so much more. It creates experienced meanings derived from pain-affected diminished capacities in engagements with objects, people, and in places. In other words, pain is contingent on its meaning in a personal environment and context or condition of interaction. It is therefore impossible to understand chronic pain without a thorough appraisal of its affective, socio-cultural, material (e.g., medication effects, technology) and spatial (home, neighbourhood, environment) dimensions. Put simply, for veterans, we move beyond a bodily model of pain to pursue a view and understanding of pain in its wider suffering (Lawer, 2021).

Responding to the first of three reasons listed above, The WHO's ICD-11 disease designation of 2022 newly classifies some aetiologies of chronic pain as long-term conditions *in their own right*, not just secondary symptoms of tissue injury/damage or neuropathic disease (Pain Research Forum, 2019). Consisting of 19 diverse clinical variants in 5 categories (Nicholas et al, 2019), it is hoped that the new designation shall promote diagnostic and therapeutic innovation having potential for better outcomes.

Heralding a major pain rethink (The Lancet, 2021), ICD-11 emboldens recurring calls to integrate psychological and social factors with biophysiological elements in clinical pain practice more fully (Sullivan et al., 2023). It is hoped that a more unified biopsychosocial (BPS) view will help to better assess, understand, diagnose and address pain's multi-factorial dimensions in its real experience.

# The need for a holistic model of chronic pain experience

Yet to date, such a view does not exist. Current models/tools are reductive, static, overly pain-intensity-based, use rudimentary psychosocial factors and lack visual sense-making capacities. They predate ICD-11 2022 and make its differentiation and treatment difficult, delayed and overly medication and costly (f)MRi scan-dependent (Fitzcharles et al., 2021). They rely on point-in-time scales and subjective patient inputs that are doubted, exacerbating care access inequities and generating stigma in the sense that sufferers are not believed when reporting their pain (ibid.). Critically, they neglect the interplay of mechanisms that actualise pain suffering and can be valid targets for multimodal beyond-bodily therapeutic innovation. Adding more complexity, co-morbid nociceptive, neuropathic and overlapping variants form "mixed pain" aetiologies (Maixner et al., 2016).

In current UK pain practice then (for civilians as well as veterans), we see a largely biomedical-oriented model still being used in NHS primary care and specialist pain clinics (including military specialists). Here psychological and social factors are generally investigated as modifiers of biological causes rather than as independent contributors to the experience of chronic pain (see Figure 2) (Sullivan et al., 2023). This "biology first" perspective has limited the applicability and effectiveness of the BPS model of chronic pain care.

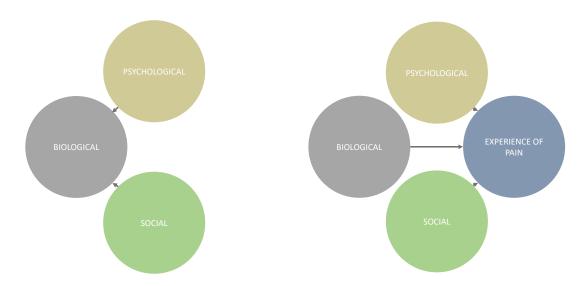


Figure 2: Current shift in chronic pain thinking from a biological-centred model (left, where pain mechanisms are moderated by psychological and social factors) to an integrative, holistic experiential model (right)

In January 2022, the new formal ICD-11 designation of chronic primary pain (CPP) (non-specific or non-injury/trauma pain) as a condition in its own right marked a breakthrough in pain classification. It underlined that pain is multi-factorial, more than bodily-biological and that interventions must go beyond a clinical/medical frame. Chronic pain problems cannot be understood apart from their interpersonal, social, material, spatial and cultural contexts of impact and meaning. To fully break free of the medical model of chronic pain therefore, psychological and social factors must now be placed on an equal footing

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with biological ones in understanding pain itself. Distinctions between <u>pain mechanisms and pain meanings</u> must be removed (Sullivan et al., 2023)

With pain now seen also as a primary syndrome (Fitzcharles et al., 2021) that can form independently of any underlying biological or physiological trauma or disease, there is a profound shift underway in the philosophy, methods and practice of pain care.

Next, we introduce the Umio model of real experience with pain and describe how it informs our research method for enquiring into veteran chronic pain real experience in the UK.

NB In the rest of the report, wherever we use the term veteran, we mean a veteran living with chronic pain.

# A model of veteran real experience with chronic pain

## The Umio model of real experience

To research, understand and improve veteran's experiences with chronic pain through novel and impactful policy, therapy, technology and other innovation, the first important task is to define a framework and method to see and know the actual experiences that veterans have when living with their pain (see Lawer, 2021). To do so, we must build a research model that identifies the many types of elements or entities that form and differentiate veteran experiences. Then we must use it to discover how the various elements interact, relate and function to originate, emerge, diverge and variously repeat veteran experiences with their pain over time, both individually and collectively.

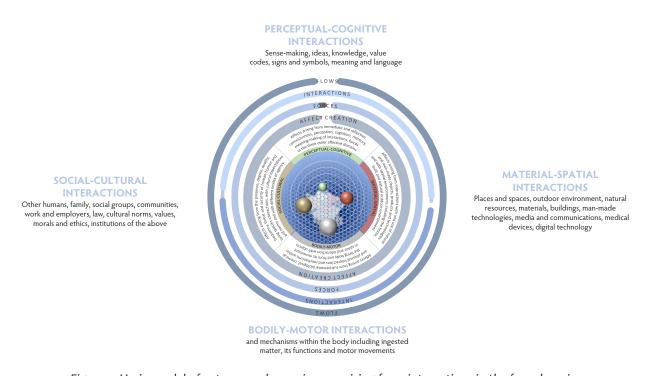


Figure 3: Umio model of veteran real experiences arising from interactions in the four domains

In Figure 3, we depict the Umio model of whole real experience consisting of four interactional domains. Each domain is comprised of distinct types or bodies of social, material, bodily, cognitive and other entities whose interaction (between and within the domains) forms actual or real veteran experiences with pain (or any chronic condition as it happens). In the dynamic moving version of the model (available in Umio videos online), the light blue / grey rings rotate around the centre to indicate ongoing experience formation via interactions within and between the entities in all four domains.

Next, we briefly describe each of the four interactional domains in the model. Doing so helps to see how the model aligns with a beyond-biological – biomedical view of chronic pain in veterans (and more widely).

## Social-cultural interactional domain

First, the social-cultural domain consists of veteran social interactions with other veterans, with their partners and families, with friends, in communities and social groups as well as with human actors or

agents within organizations of all types. They include interactions with professional health care and pain specialist agents in physical or virtual clinical and care practices. Social interactions of veterans tend to follow certain standards, habits, routines and activities shaped by military training and mindset, and other cultural norms, signs and symbols, ethics and morals, roles, identities, values, institutional arrangements and rituals. veteran interactions with non-human species (e.g., pets – supplied by some veteran charities) are included here too.

# Material-spatial interactional domain

Second, the material-spatial domain consists of veteran interactions with man-made objects such as consumer products (e.g., food packaging), buildings including the home and its functional spaces such as the bathroom, stairs, and beds, vehicles including cars and tools (e.g., cutlery, DIY). Material entities also include data, information, communications and media technologies (analogue and digital), medical and other product devices, as well as veteran interactions within and movements through real and virtual (online) spaces and places, whether in natural or built environments.

# **Bodily-motor interactional domain**

Next, the bodily-motor domain consists of organismic interior interactions and mechanisms of molecular, cellular, tissue, organ and musculoskeletal functions and matter within the body, including those arising from motor functioning and movement of the body, its situation and posture. This is the domain of musculoskeletal and neuronal system mechanisms of injury, trauma or damage giving rise to pain. Included too in this domain are interactions of the body's *consumption*, use and conversion and output of external natural matter and energy such as food, water, air, light and heat and also of ingested or topical pain medications (located in this domain as they are administered into or absorbed by the body).

# Perceptual-cognitive interactional domain

Finally, the perceptual-cognitive domain consists of veteran immediate and reflective perception and sense-making as well as cognition, memory, representation and interpretation of interactions in the other three domains. Perception is seen from the point of view of action and of potential affordances or possibilities for new interactions with bodily and motor, social and cultural, material and spatial entities in the other three domains. Cognitive interactions include semiotic and discursive encounters with pain representations, images, ideas, information, signs and symbols. They include the language veterans use to express their chronic pain sensations and impacted experiences, interpret and explain their meaning and justify their choices and actions. They also determine how and why veterans value the different entities they interact with in the other domains. They shape how veterans sense, assess and determine the extrinsic or intrinsic worth of interactions – the things they do or would like to do in their lives.

# Thinking and seeing beyond a biomedical model of veteran pain experience

Using the four interactional domains and two horizontal and vertical axes, the Umio holistic model of real experience supports two fundamental perspectival adjustments in our system of knowing and acting on veteran experiences. Simply put, these are "seeing inside" and "seeing outside":

- **Seeing inside:** We are drawn to the centre of the model as the space where the four domains interact to variously produce, differentiate and reproduce states, qualities and tendencies of action-doing in the real experience of veterans. Here we see real experiences with pain as the product of the interior interaction of the four domains.
- **Seeing outside:** We are drawn to the exterior domain of social-cultural and material-spatial entities and the forces and tendencies they bear that shape veteran real experiences with pain and other health conditions, especially their mental health including PTSD. Here we see real

experiences with pain, health, disease and illness as the product of forces of the outside as well as in their interior mind-body intersection. We become interested in external ideas, tendencies, forces and conditions that veterans interact with and that originate and variously recur their different experiences with pain.

In making these two perspective shifts, we see how diverse veteran real experiences actually *become different* via forces and tendencies in the interplay of their interior and external interactions. Such a radical mode of seeing veteran experience starts with the widest outside-in, beyond-the-body and beyond-the-person (and certainly beyond the patient) perspective. Now **Veteran Real Experience** is the primary phenomena of interest, not individual veterans as such.

# The generative material of veteran pain experience: Affect

A second fundamental aspect of the model identifies the generative material that form, sediment in and differentiate veteran experiences arising from their ongoing interactions within and between the four domains. This material are termed *affects*. They have two related dimensions and roles in veteran (and any) real experience: sensations and capacities.

- Affects as sensations: Affects are sensations, feeling states and impressions that mark transitions within and between experiences with pain states. Actualized via interactions in the four domains, affects themselves interact, combine and can fuse together to qualitatively differentiate and variously stabilise and reproduce veteran experiences with pain.
- Affects as capacities: Affects also determine what a veteran can be and do, or their potential capacity to affect or be affected in interactions within the four domains. As an affective capacity, affects are a veteran's power for creating and acting in and upon an experience with chronic pain, whether to be affected or to affect positively or negatively when entering into relations and interacting in the four domains.

In Table 1, we show examples of pain *affects as sensations* and *affects as affective capacities*. These are drawn specifically from the recent qualitative research into Veterans experiences (see section below) as well as past Umio chronic pain studies.

With a whole, dynamic and interactional model of Veteran real experience now defined as our base research framework, we can now determine how such a model informs the scope and purpose of how we can improve veteran experiences. We call this **Expansive Wellbeing Creation** and introduce it in the next section.

Table 1: Example affects and affective capacities from Umio veteran qualitative research organised by the four interactional domains.

DOMAIN	AFFECT AS SENSATION	AFFECT AS CAPACITY
SOCIAL- CULTURAL	<ul> <li>Sense of being blamed by others</li> <li>Sense of not belonging to a social group</li> <li>Sense of rejection</li> <li>Sense of unwanted loneliness (itself a social construct)</li> <li>Sense of being a burden or of dependency on others</li> <li>Sense of loss of intimacy with a partner</li> <li>Sense of grief at loss of partner</li> <li>Sense of isolation or withdrawal from social life</li> </ul>	<ul> <li>Capacity to work regular hours / to a routine</li> <li>Capacity to socialise with others</li> <li>Capacity of dependents (and their dependents) to be socially mobile</li> <li>Capacity to obtain useful help with pain when needed</li> <li>Capacity to find and choose suitable employment when living with pain especially in veteran transition)</li> </ul>
MATERIAL- SPATIAL	<ul> <li>Sense of unwanted dependency on a digital technology</li> <li>Sense of being quantified or objectified by data</li> <li>Sense of anxiety when outdoors in the local neighbourhood</li> <li>Sense of insecurity in my own home</li> <li>Sense of losing control of medication use</li> <li>Sense of material deprivation</li> <li>Sense of having limited movement</li> </ul>	<ul> <li>Capacity to avoid a dependency on technology to intermediate social connections</li> <li>Capacity to use digital pain self-management tools</li> <li>Capacity to choose suitable places and spaces to visit or navigate in built environment</li> <li>Capacity and desire to leave the house</li> <li>Capacity to be comfortable in the home</li> </ul>
BODILY- MOTOR	<ul> <li>Sense of pain arising from a persistent load on a part of the body</li> <li>Sense of pain arising from a primary pain syndrome, e.g., fibromyalgia</li> <li>Sense of pain arising from trauma, whether injury or surgery-related</li> <li>Sense of pain linked to specific activity/motor movement</li> <li>Sense of low or no physical energy</li> <li>Sense of loss of bodily strength</li> <li>Sense of fatigue</li> </ul>	<ul> <li>Capacity to take compensatory actions to reduce pain that work consistently</li> <li>Capacity to appropriately question / challenge GPs advice</li> <li>Capacity to communicate (veteran) pain experience and affects to GP/clinicians</li> <li>Capacity to access / obtain pain care and support when needed</li> <li>Capacity to understand relationship between intensity of activity and a pain response</li> </ul>
PERCEPTUAL- COGNITIVE	<ul> <li>Sense of lost personal identity</li> <li>Sense of always waiting for something to happen</li> <li>Sense of loss of personal autonomy</li> <li>Sense of lost pride</li> <li>Sense of unfinished service</li> <li>Sense of living day-by-day or only in the present</li> <li>Sense of a loss of power</li> <li>Sense of diminished free will or freedom</li> <li>Sense of a lack of progress</li> <li>Sense of diminished hope</li> </ul>	<ul> <li>Capacity to develop a useful "pain memory"</li> <li>Capacity to see pain and its causes as "beyond the body"</li> <li>Capacity to identify and recall personal physical/motor factors forming an experience of pain</li> <li>Capacity to understand how personal outlook / mindset affects pain experience</li> <li>Capacity to achieve effective pain selfmanagement negated by non-pain affects</li> </ul>

# Introducing expansive veteran wellbeing

If we are work to with a more holistic, beyond-bodily view of chronic pain in its experience in the veteran world, we need a more expansive view of purpose or creation in our veteran policies, organisations, plans, practices and actions. We call this normative goal, expansive wellbeing. It signifies the most positive, dignified, fulfilled and flourishing state of veteran living, being or existence.

Drawing on Nussbaum (2009), expansive wellbeing consists of ten inter-relating desired elements forming a valued, liveable and meaningful life. Briefly, these are as follows:

- **Desire for a full life duration** the desire for physical survival and to live to the end of a normal human life, not dying prematurely or to have one's quality of life reduced to the extent that life is not worth living.
- **Desire for bodily vitality** the desire to have and enjoy good health including reproductive health, to be adequately nourished with access to a variety of healthy foods and to have adequate, safe and secure shelter.
- **Desire for bodily integrity** the desire to be able to move freely from place to place, to be secure against physical or sexual violence or abuse, to have opportunities for sexual freedom and satisfaction and to have ethical and moral choice in matters of reproduction.
- **Desire for experiencing, creativity and learning** the desire to imagine, explore, think and reason in a human (not machine-like) way that is informed and cultivated by an adequate education and that allows a desire to experience, create and produce ideas, thoughts, works and events of one's own choice and interest, and that are guaranteed by political, religious, spiritual and artistic freedom of expression and exercise of mind, and without non-beneficial pain.
- Desire for emotional attachment the desire to form and have attachments to things, places, spaces and persons outside ourselves; to love those who love and care for us, to grieve, to experience longing, gratitude and justified anger and to develop emotions free of fear and anxiety in relationships with others.
- **Desire for practical reason** the desire to conceive of the good, to engage in critical reflection of one's experiences and to plan and conceive of purpose and to change one's own lived experiences in the future.
- Desire for social connection and engagement the desire to live for, with and towards others, to recognise and show concern and empathy for others, to form social connections and interactions and to be treated by others with dignity, respect and without discrimination or prejudice.
- **Desire for connection and engagement with nature** the desire to live and act with concern for nature and to form a mutually beneficial connection with non-human species and the natural environment.
- Desire for play and fun the desire to laugh, have fun and enjoy recreational, sports and leisure activities.
- Desire for equal recognized participation and free rights (freedom) the desire to have freedom over one's environment, including political freedom and freedom of expression of political ideas and self, to hold property and rights to material goods on an equal basis, and to access and have work on an equal basis and recognition with other workers without exploitation, discrimination, bias or injustice.

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With the elements of expansive veteran wellbeing defined, next we can regroup them into each of the four interactional domains forming the holistic model of real experience (Figure 4). Doing so provides a means to discern purpose and scope of assessment and action in each of the four domains of veteran experience as well as overall.

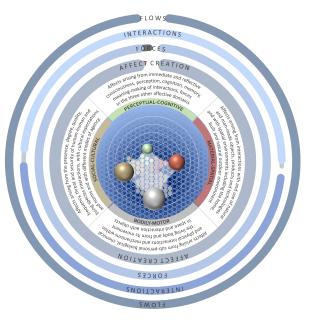
The final research concept used in our method helps us to see differences in veteran affects, capacities and potentials for expansive wellbeing. Next, we introduce this assemblage thinking and concept.

#### PERCEPTUAL-COGNITIVE AFFECTIVE REGISTER

Imagine, explore, think and reason | Adequate education
Experience, create and produce ideas, thoughts, works and events of one's own choice and interests
guaranteed by political, religious, spiritual and artistic freedom of expression | Grieve, experience
longing, gratitude and justified anger and to develop emotions free of fear and anxiety | Conceive of
the good, to engage in critical reflection of one's experiences and to plan and conceive of purpose and
to change one's own lived experiences in the future

#### SOCIAL-CULTURAL AFFECTIVE REGISTER

Secure against physical or sexual violence or abuse | Sexual freedom and satisfaction | Ethical and moral choice in matters of reproduction | Form and have attachments to persons outside ourselves | Love those who love and care for us to live for, with and towards others, to recognise and show concern and empathy for others | Form social connections and interactions and to be treated by others with dignity, respect and without discrimination or prejudice | Access and have work on an equal basis and recognition with other workers without exploitation, discrimination, bias or injustice | Have freedom over one's environment, including political freedom and freedom of expression of political ideas and self



#### MATERIAL-SPATIAL AFFECTIVE REGISTER

Adequate, safe and secure shelter | Form and have attachments to things, places, spaces outside ourselves | Live and act with concern for nature and to form a mutually beneficial connection with non-human species and the natural environment | Laugh, have fun and enjoy recreational, sports and leisure activities | Hold property and rights to material goods on an equal basis

#### **BODILY-MOTOR AFFECTIVE REGISTER**

Physical survival / full expected life duration | Not dying prematurely | Not have one's quality of life reduced to extent life is not worth living | Good bodily health | Reproductive health | Adequate nourishment | Ability to move freely in places and environment

Figure 4: Expansive wellbeing elements organised around the four domains in the model of real experience.

# **Assemblages of different Veteran experiences**

# Differences in Veteran capacities for expansive wellbeing

Above, we introduced the concept of affective capacity, defining it as the power of acting and creation in real experience. Adding the idea of expansive wellbeing, we can see how affective capacity denotes a veteran's desire and potential to strive towards, realise and sustain one, many or ideally all of the ten elements forming a rich, meaningful post-service life.

In any condition context, affective capacities for expansive wellbeing creation vary. Some veterans have more potential affective capacity (in this case to change their experience with chronic pain) and therefore greater powers of wellbeing creation, whereas others have little. A lack of or suppressed affective capacity can lead to the development and recurrence of chronic pain amongst veterans due to diminished powers of acting on injuries and trauma and from stress or anxiety in everyday interactions (such as with the general public, at work and with healthcare organisations). These affects can disable or limit veteran affective capacities and reinforce existing trauma and pain experience states by suppressing levels of veteran energy, desire, motivation and potential action.

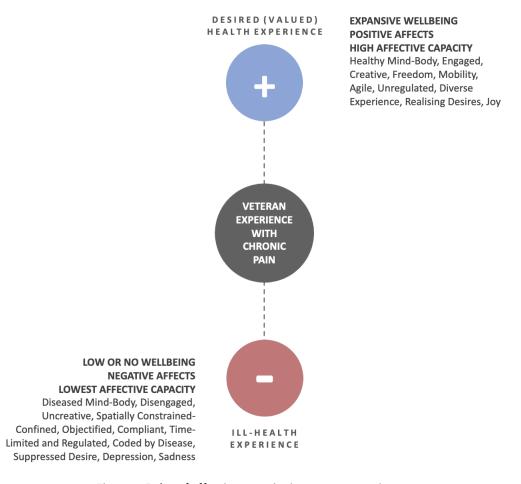


Figure 5: Poles of affective capacity in veteran experience

In the collective body of almost 1m veterans living with chronic pain, we can identify extremes or opposite poles of positive and negative qualities and affective capacities of expansive wellbeing, as follows:

- A negative, ill-health experience pole that defines the worst affect quality and affective capacity of chronic pain. Here, there is a stuck flow and low veteran capacity to act when living with chronic pain, an experience of dis-ease and being stuck that diminishes a veteran's power or capacity of acting and wellbeing creation.
- A desired (most-valued) experience pole that contains the most desired qualities and affects and veteran affective capacity. Here there is an intensity of affect creation, an intensity of diverse positive experience that reinforces an ongoing power or capacity of acting forming expansive wellbeing a rich, valued life.

In Figure 5, we depict the two poles together with brief descriptions of the opposing qualities of affects and affective capacities characterising each.

# Applying the model to veterans

For veterans living with chronic pain, some are able to achieve a degree of sustained freedom from pain and to live well. They have a more positive wellbeing experience despite ongoing pain. Others however become severely debilitated and isolated by their pain. Their capacity to affect their pain is limited.

On the next two pages, we visually represent these contrasting affect qualities and capacities. Figure 6 depicts the negative ill-health lived experience of a veteran who is limited and controlled by their pain. They have a debilitating, chaotic and socially isolating chronic pain experience, characterised by affects of (amongst others) episodes of unpredictable undiagnosed intensive pain, poor sleep and increased fatigue, low energy, a reduced capacity to plan ahead, to work and to socialise and a loss of a sense of purpose. They may have PTSD and sometimes experience suicidal thoughts. For this person, their sense of time in their real experience has slowed down. Their affects forming experience are stuck, intense and confined (shown conceptually in the centre of the model). The person has become over-coded by their pain and their affective capacity is poor.

By contrast, Figure 7 depicts the experience of a Veteran who is able to live well with chronic pain and enjoy a degree of sustained freedom forming a meaningful life. They have a well-developed affective capacity that has allowed them to overcome their pain, a capacity characterised by (amongst others) lower pain intensity, better sleep at night-time, more active social engagement, an improved ability and motivation to work, greater acceptance and understanding of their pain and overall, a greater sense of hope for the future.

# MOST NEGATIVE PAIN AFFECTS

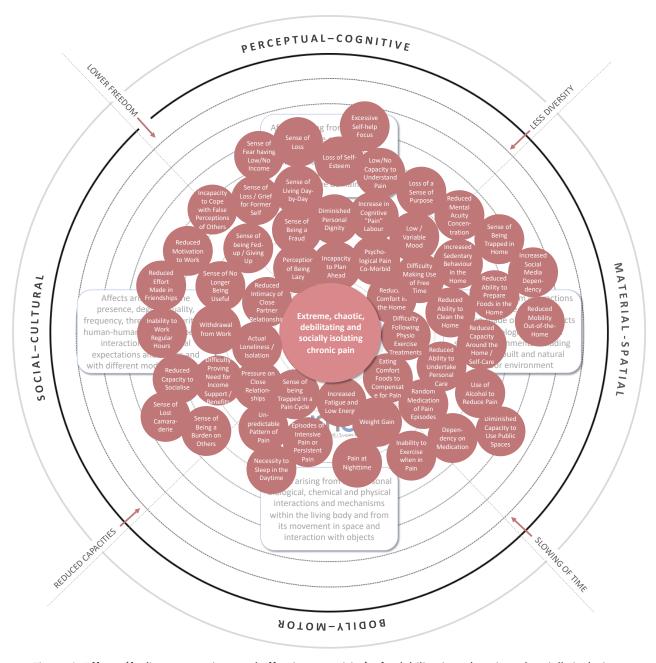


Figure 6: Affects (feelings, sensations and affective capacities) of a debilitating, chaotic and socially isolating veteran experience when living with chronic pain.

MOST POSITIVE

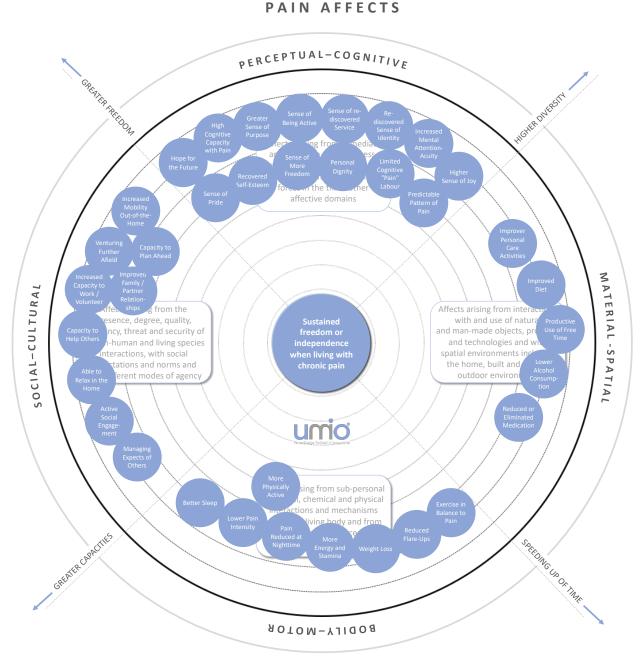


Figure 7: Affects (feelings, sensations, qualities and capacities) of a veteran living well with chronic pain and enjoying a degree of sustained freedom from pain.

# Beyond pain intensity to affect as differentiator

Note that in the Umio research and design perspective, difference in veteran experience is defined by varied affects and affective capacities rather than more typical clinical, objective, quantitative, intensive measures and bodily-site location models of pain. In an affect view, qualities of experience transcend quantitative measures by defining not only an individual veteran's general state of pain experience but

also their potential capacity to recover or improve that experience. This is true for any focal chronic condition context.

# Introducing assemblages of real experience

Using the view of two poles of most positive and negative veteran experience, we can now look between the poles (in our research) to discern different states of qualities of experience in the veteran population. Figure 8 depicts six distinct yet contingent and variously recurrent dynamic states of experience quality and capacity *between* the two poles of pain ill-health and desired, valued pain experience described above. These states or assemblages are (moving towards the negative pole on the right-hand side) *at risk, worsening* and *chaotic* and (moving towards the positive pole) *emerging, building* and *stable*. Also, it is possible to zoom into a single state and find further differentiated states).

Such an assemblages of experience perspective helps to explore how similar states and capacities of veteran real experience originate, emerge, differenciate, persist and may decline over time – a developmental or longitudinal model. Also, it helps to see movements from one state to another and the forces and interventions that can power those movements, stabilise or hold them back. It forms a novel view of the formation and emergence of an entire dynamic realm of veteran experiences. This view is the operational mechanism of the Umio experience ecosystem platform.

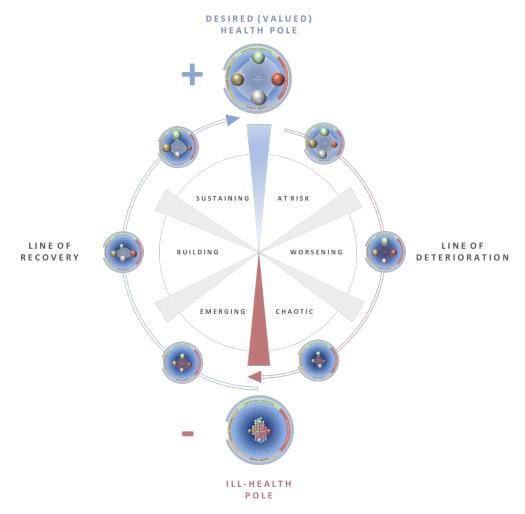


Figure 8: Assemblages of real experience with chronic pain

Figure 8 also depicts two "lines of becoming" that denote the primary directions of movement or transition between the assemblages of veteran experience. These are:

- A (red) **line of deterioration** from the at risk to the chaotic state (on the right-hand side)
- A (blue) **line of recovery** from the chaotic state to the stable state of expansive wellbeing (on the left)

We can also envisage points of stabilization in each assemblage. These hold, limit or prevent transition from one assemblage to another. They can lock an experience in either a positive (healthy stability) or negative (ill-health stuck) state - or somewhere in between.

# Applying the three Umio research concepts

Using the three Umio research concepts – holistic interactional model of real experience, expansive wellbeing and assemblages thinking - we can research and understand how veteran real experiences with pain originate, emerge, differentiate, persist and change over time. Such a developmental or evolutionary view of real experience formation supports the following new perspectives and activities (in bold).

- 1. First, we can explore how, when and why certain veteran experiences tend to *originate* and also why they *tend to persist*. This helps to design policy and strategy that targets the conditions and mechanisms of formation, persistence, deterioration and recovery of veteran experience.
- **2.** Second, we can determine the *approximate distribution* of veterans (we do this below) within the different assemblages, i.e., the number and percent in the *at-risk* state, the number and percent in the *worsening* state, the number and percent in the *chaotic* state, and so forth. **This insight supports** a more informed review and reallocation of veteran resources.
- **3.** Third, we can discover and better understand the *quality, intensity and patterning* of affects and affective capacities present within assemblages of veteran experience between the poles. **Having knowledge of these supports a more nuanced and differentiated view of the design, types, fitness and value of resource deployments within the different assemblages.**
- **4.** Fourth, we can assess the various ideas, tendencies, forces, interactions and factors that are *affecting veteran* capacities (positively or negatively) to prevent, recover or stabilise their experience with pain on a longitudinal basis.
- **5.** Fifth, we can identify *gaps in current knowledge* of the different states of veteran experience. We can see where *existing knowledge* is held by particular stakeholders or groups (for example knowledge of veteran disability is held by professional actors in the healthcare system whereas knowledge of the at-risk state is held by professional public health system actors). **We can rethink and redesign individual, organizational and system-level priorities, responses and capacities for addressing veteran experiences.**
- **6.** Finally, we can learn how, where and why forces present within different assemblages of veteran can blind us to *seeing novel paths and possibilities* for transitioning those assemblages. **We can identify which forces are stuck, which to change and which or where to pursue new paths to expansive veteran wellbeing creation.** This is exactly what we plan to do via the Umio experience ecosystem.

With the three primary Umio research concepts now introduced, and the range of possible applications briefly outlined, we can now present our research into actual or real veteran experience in the UK.

#### Veteran research

#### Introduction

In March/April 2023, 15 semi-structured, one-hour qualitative telephone interviews were undertaken with male and female veterans of mixed age and from all three service affiliations, and with present enduring experience of chronic pain. The purpose of the research was to develop an in-depth understanding of diverse veteran real experiences with pain via open questioning using the Umio research and design concepts and a loose discussion guide (see Appendix One). This was then followed by iterative thematic analysis to produce a model of different veteran outlooks on their pain and how they manage it.

# Participant sample

Participants were recruited by a professional fieldwork agency based in Manchester using a sample matrix supplied by Umio (Table 2). This specified the criteria for recruiting a diverse mix of participants. These were that veterans had to have served in one of the three forces for at least six months, be older than 30, live permanently in the United Kingdom, have been fully discharged for at least six months, and have had chronic pain for at least three months with it having an impact on their lives. The pain did not have to be highly intensive, severe and/or persistent, but did have to be regular (at least every few days).

Four veterans with PTSD were also recruited (not shown in the matrix as these were added later). Two veterans had attempted suicide. Veterans with non-specific chronic pain beyond a single bodily site were sought and pain did not necessarily have to originate in military service (we wished to explore how the service may have exacerbated pain or a pre-existing disease). However, the majority of pain did arise in service. Finally, no veterans were to be older than 60. Officers were not represented within the sample.

Table 2: Basic recruitment sample matrix

			AGE		OF WHI	CH (ANY)	OF WHIC	H PAIN TYPE
British Army	NO.	31-40	41-50	51-60	Black	Asian	Specific	Non-Specific
Male	3	1	1	1				
Female	2	1	1					
TOTAL	5	2	2	1	1	0	3	2
			AGE		OF WHI	CH (ANY)		
Royal Navy	NO.	31-40	41-50	51-60	Black	Asian	Specific	Non-Specific
Male	3	1	1	1				
Female	2	1	1					
TOTAL	5	2	2	1	0	1	3	2
			AGE		OF WHI	CH (ANY)		
Royal Air Force	NO.	31-40	41-50	51-60	Black	Asian	Specific	Non-Specific
Male	3	1	1	1				
Female	2	1	1					
TOTAL	5	2	2	1	1	0	3	2

The professional market research agency approached veteran charities, local community veteran outreach groups and other bodies to publicise the research and recruit participants. Veterans were paid a small honorarium to take part. The recruitment was straightforward and there was no shortage of willing interviewees. Participants came from England, Scotland, Wales and Northern Ireland.

#### **Ethics**

Informed consent was given verbally by all veterans to the study recruiters by telephone prior to their interview. At this first contact, all participants were informed and understood that the research was confidential, and that all captured data would be anonymised. All participants were asked again for consent at the beginning of each interview and anonymity re-explained. Permission to audio-record the interviews was also sought. All respondents consented and none withdrew from the interviews.

# Research purpose and method

The primary purpose of the research was to inform the proposition, content and design of the Umio Veteran Pain experience ecosystem. We also wished to explore the presence and nature of veteran acceptance and commitment to living with pain. This necessitated probing of veteran experiences using the four interactional domains of real experience in the Umio model and also our assemblage thinking. Not all themes could be explored in each interview due to time limits but a sufficient cross-section of insights spanning them was obtained. The primary themes explored and reported are shown in Table Three. Others were also captured but these are not produced in the report for reasons of length.

Table 3: Research themes by interactional domain

Bodily-motor	Perceptual-cognitive	Material-spatial	Social-cultural
Pain sites Pain origins Pain medication	Veteran attitudes to pain linked to military mindset Pain outlook and approach Pain knowledge Help-seeking behaviour or outlook	Home Transport Travel Environment	Family Friends Loneliness-Isolation, Work Healthcare Veteran Charities Other veteran interactions

Next, we summarise the chronic pain profiles of the 15 participants.

## Participant pain profiles

Participants ranged from 34 to 68 years of age, with a mean age of 47. Length of service ranged from 2 to 27 years with a mean of 11 years. Interviewees had been medically discharged (11) and completed normal service (4); all those medically discharged left the service because of an injury or trauma which now is responsible for their chronic pain. Four participants served in the Royal Navy, six in the Royal Air Force and five in the British Army.

## Pain sites

Participants reported they experienced pain from a wide range of bodily sites (Table 4). The most common sites are lower back (12 participants), knees (9), spine (4), hips (3) and shoulders (3). Four reported chronic primary pain. Three had a pre-existing immuno-inflammatory or arthritic disease that was undiagnosed or unknown prior to their service, and that had become exacerbated during and after their military service.

Table 4: Reported bodily sites of chronic pain

Feet	2
Ankle	1
Knee(s)	9
Hip(s)	3
Upper Back	1
Lower Back	12
Spine	4
Shoulders	3
Neck	2
Arms	1
Hands-Wrists	2
Headaches	1
Nerve Damage	1
Widespread	4
Pre-Existing Disease	3

Of the 15 veteran participants, 13 had more than one bodily site or location of their pain (87%). One had 5 pain sites and two had 4 sites. These can be indistinguishable. Four reported widespread chronic pain that is likely to be primary (as per the ICD-11 designation of chronic primary pain discussed above). The average number of pain sites was 2.7. This identifies the need for joined-up whole body or multi-site thinking when assessing veteran experience with pain.

# **Pain origins**

Most knee pain was experienced in the RAF veteran group (4 out of 6 participants). The majority of them incurred knee problems arising from lifting and moving heavy equipment (e.g., missiles) on and off aircraft combined with the frequent need to bend, crouch and manoeuvre in enclosed spaces. All British Army participants reported lower back pain problems due to the demands of carrying heavy equipment and exposure to extreme weather. Long-term pain arising from assault course injuries and accidents was also found to be common. Table 5 provides a brief explanation of the events or causal factors that each participant explained as the origin of their current chronic pain.

# A note on veteran participant coding

Note the coding used in the table to designate a participant works as follows. The first letter stands for the service identifier: A for Army, R for RAF and N for Royal Navy. The middle number is the participant number within the service group (1 to 5 or 6). The final letter indicates a participant's declared gender, M-Male and F-Female.

Table 5: Reported origin causes or events of current chronic pain

N1F	PT assault course injury
N2M	Fall from helicopter in active duty
N3F	PT assault course injury
N4M	General heavy maintenance work on a ship
R1M	Carrying heavy kit in cold weather; general wear and tear; foot slogging
R2F	Lifting heavy equipment
R3M	Clamouring in and out of small spaces in aircraft plus PTSD
R4M	Loading freight
R5M	Lifting and moving oil drums / barrels; pulling cables; cold weather
R6F	During basic training
A1M	Jumping from a height and landing; general wear and tear, and ill-fitting boots; heavy equipment
A2M	Injury, landing, running
A3F	Lifting heavy equipment including office equipment such as filing cabinets
A4F	Unknown origin
A5M	Carrying weights in heat plus civilian car accident and PT injury

## Two veterans explain their particular origin story:

It's really quite heavy going work. Although we had tools and straps and lifts and hoists, it was still quite a very physical role. At this point in time, I was the only female weapons engineer within the squadron, so it was kind of looked upon as I needed to be up there with the boys. These boys were built like sheds - six foot seven – proper stacked guys and then there's tiny little me. So I did my absolute utmost to match them. It's a health and safety nightmare. We had these big old tall boxes – "two man lift" it says - but if you're not manhandling it out from the hangar to where the aircraft is on your own, I didn't want to be seen as the weak link in the team. There were just some things that I just physically couldn't do that even these boys would take some effort to do. It came to a point where I was like look, you're just gonna have to help me (R2F).

You're doing a physical job and all those stresses and strains are carried through your back, your shoulders and neck. So unbeknownst to me all of these little things starting to really kind of add up. And you'd go home, and you'd be aching but you'd just shrug it off (A1M).

In the next section, we explore the impacts of chronic pain in veteran real experience. We organise our analysis by the four domains forming the Umio real experience model (see Figure 3). These are: Bodily-Motor, Perceptual-Cognitive (Psychological), Material-Spatial and Social-Cultural. We

intersperse our findings with direct quotations from interviewees to help bring the data and insights to life.

# Research findings

# **Bodily and motor-movement domain findings**

All participants reported that they experience pain regularly at least every few days. The vast majority experience constant chronic pain that persists as a dull ache yet then suddenly flares up either in response to certain movements or activities, stress and anxiety, trauma, or cold weather, or unpredictably.

I'm kind of hunched over my shoulders. My back is aching, and I start to walk funny because I'm trying to hold myself in such a way that it's just not natural, but I don't want to hurt anymore, and the pain is constant. I have permanent headache that I could not get rid of. It's really not okay (N2M).

In terms of impacts on their bodies and their ability to move and function, the majority of participants reported high degrees of negative impairments variously to their general levels of fitness, to their weight, to sleeping ability and hours (leading to daytime fatigue), to their ability to walk reasonable distances (more than 50 yards), to running (a big loss to many who wish to run to stay fit after their service – three actively running participants have had to stop running), to playing team sports, to sitting for prolonged periods, to standing for a short time, to walk idly at a slow pace (such as when shopping with their partner). Many reported difficulties performing daily personal functioning tasks such as showering, bathing and washing hair.

I lose feeling in my hands and stuff so going for a shower, washing your hair - it really takes it out of me. Washing my body, all those shoulder movements that people take for granted. Washing up. It's all those big movements. Hanging out the washing on the line in the garden when we get some sun. Mowing the lawn - just general day-to-day stuff. Anything that needs lifting. Taking the laundry upstairs after emptying the washing machines, cooking can all be draining. You have to go through the pain to get it done because you know you can't just not do it nor expect others to continuously do it (**R2F**).

As a consequence of having impaired levels of physical fitness and movement, two participants had become obese, had developed high blood pressure and type 2 diabetes.

I gained one or two pounds a month every year and then the next year it started to become four. I've got to the point where I am in the morbidly obese category now, and with that comes more complications. It is a direct result of the injury versus my own issues on top. (N1F).

#### **Pain medication**

13 of the 15 veterans in the study take medications to alleviate their pain on an as-needed basis, in response to flare-ups or pre-emptively prior to undertaking bodily activities. About half were content to continue medicating, and half wished to come off medication due to a fear of becoming addicted. Three participants admitted they used alcohol to medicate away their pain (NB: Not all were asked directly, this information was volunteered only so the instance of alcohol use may be higher). One veteran talked about his medication and overdose experience.

When they discharged me from the hospital, they loaded me up with these tables and also four bottles of OroMorph. Instead of taking it every 4 hours - sticking to 50 ml - I taking it every 2 hours. I was getting addicted to it. I got so bad that all the paint stops and I thought oh that's great, I'll go back to work. Then I had a drink and that was it. For 3 days I was doing cold

turkey, and I lost nearly three and a half stone. I was rushed back into the hospital because of the diarrhea, and I was vomiting all the time (**N4M**).

Altogether we have identified several bodily-motor domain impacts and dimensions of veteran real experience. These are shown in Appendix Two.

# Perceptual-cognitive domain findings (veteran pain psychology, outlook, mindset)

In the second section of findings, we discuss the psychological aspects and impacts of chronic pain in veterans. These link to veteran individual and collective perceptions and cognition of their pain, particularly their sense of self, their thoughts and outlook (on living with pain and generally), their goals, their ideas about and knowledge of pain (and desire to seek more knowledge), and their memories and reflections on their time in service.

# Veteran attitudes to pain linked to their "military mindset"

All participants clearly articulated various common traits of their military training, culture and conditioning in their attitudes to their pain and its management, and life generally, albeit in different degrees. Some had begun to develop a more civilian attitude and outlook to their pain. Two mentioned their military mindset was generational, being passed onto them by their service parents.

A military mindset is commonly depicted as spanning a set of linked perceptions, ideas, values, senses and attitudes towards self-image, self-weakness, problem-solving, "doing" activities, how well activities are done or should be done by oneself and others, help-seeking and helping others. The refrains "no pain no gain" and "train hard, fight easy" (meaning that enduring high levels of pain is a sign of high or optimal operational performance) were frequently mentioned by participants, especially male veterans.

The simplest way to state these dimensions forming a military mindset in veteran perceptions or senses of what it means to be a veteran are to list them, in no particular order:

- Strong sense of pride
- Sense of self-reliance
- Stoicism
- Building personal efficacy
- Optimising
- Solving problems and not letting them dwell or spend lots of time analysing them
- Solving problems as a team
- "Just get on with it" mentality
- Not displaying personal weakness in front of others
- Expecting others to do as they say they will do
- Expecting a high standard of performance when doing an activity
- Using humour to detract from a bad or worsening situation
- Mocking others (banter) who do not exhibit the above traits, whether at all, consistently or strongly, e.g., those who take sick leave, especially for bad backs

As reported elsewhere, the military often shapes beliefs and attitudes to personal health care and to pain itself, creating the sense of needing to ignore any pain and avoid obtaining help (Denke and Barnes, 2013). Here is a pertinent quote from one veteran:

Time in service or in my case what I learned from my parents as role models, and you know the people around you, is that military people somehow achieve things that most people would get no chance to do because they have that different mindset. But that mindset in itself cripples you if you have physical or mental health problems later because that same mindset doesn't work. Yeah, you know the mindset to encourage you to do things on a broken body. Why would I want to do that - but I did - and I was more frustrated that I couldn't do it as elegantly as I wanted. They (the military) ground into that you want to please so greatly that you will push your body beyond reasonable levels (**N1F**).

It is however important to emphasise that not all veterans share or display all these aspects forming a military mindset universally. For any single trait, nor do they do so in the same degree. We must acknowledge there are differences in military mindset that translate into different veteran outlooks on their pain, which then may or may not influence or give impetus to a given approach to its management. Next, we describe these different approaches.

# Veteran pain outlooks and approaches

In this research, based on careful thematic analysis of each veteran's pain situation, thoughts, beliefs, desires, attitudes and activities, we identify five veteran pain outlooks. Each translates roughly into a certain purpose and content of approach to personal pain "management" (or its avoidance or non-management). The five forms are:

- 1. Cognitive fusion
- 2. Experiential avoidance (pain suffering elimination)
- 3. Pain relief, avoidance, control, fix and cure (symptom reduction and rehabilitation)
- 4. Self-focused proactive pain problem-solving
- 5. Acceptance and commitment to the pursuit of a meaningful life despite pain

Next, we discuss each.

## **Cognitive fusion**

The first outlook can be an overwhelming veteran disposition. It is defined by a sense of anger and loss felt by veterans that leads them to take little action to get help, deal with or manage their pain. Veterans may feel bitter about what has happened to them (and those who maybe failed them), especially if they have left their service – their career – prematurely due to a medical discharge because of an injury and its ongoing pain. Frustration at not being able to engage in or enjoy past activities such as sport or teamwork may predominate. This can be coupled with a sense of sadness and regret when comparing their current pain-inflicted selves with their former selves.

In this real experience, pain is fused with all the experiences and impacts felt by veterans. Cognitive fusion means that a veteran finds it difficult to separate their pain from their thoughts about what it meant to be in the military, the difficulties they experience in their adjustment to becoming a civilian and the ongoing sense of loss, frustration and diminishment in their life. Pain becomes welded to all their thoughts about being a veteran; it is bonded to all their affects or sensations of transition and struggles at ongoing adaptation, restricting their capacities and motivation to move forward.

This outlook can dominate a veteran's experience. It can also return or resurface in response to certain negative events or interactions (e.g., a poor health care encounter or a failed surgery). When it exists, veterans stop engaging proactively and constructively with their pain. Depression and anxiety are common responses as well as more pain suffering. Veterans diagnosed with PTSD are more likely to have this particular psychology.

Cognitive fusion can persist in all veteran's lives in different intensities and kinds. **One veteran** in our research described how at times they felt like giving up as the pain and the struggles of adjustment to civilian life had become overwhelming.

# **Experiential avoidance (pain suffering elimination)**

Experiential avoidance is when a veteran tries to deliberately avoid, get rid of, suppress, or escape from their pain and the negative thoughts of suffering that come with it. Such avoidance acts as a psychological safety measure to avoid experiencing negative affects and emotions. However, addictions can emerge from their short-term efforts to remove unwanted pain-associated thoughts and feelings such as boredom, loneliness, isolation, anxiety, guilt, anger, sadness, and so on. Gambling, drugs, alcohol, and substance abuse help veterans to avoid or get rid of these pain-induced or -related feelings temporarily (via symptom reduction), but in the long run, more pain and suffering can result. While immediate gains may be realised (i.e., no pain), the long-term costs of relying on potential addictive medications, alcohol and other substances and activities include psychological dependence, possible physical addiction, other physical and emotional side effects, financial costs, relationship costs, and a failure to learn more effective responses to pain, which therefore maintains or exacerbates the issue.

In this research, one veteran has this outlook.

## Pain relief, avoidance, control, fix and cure (symptom reduction and rehabilitation)

A pain relief, avoidance, control, fix and cure outlook is where a veteran takes active steps to control the intensity of their pain by avoiding and/or moderating their activities and interactions on an often daily basis. It is an attempt to improve their short-term quality of life through directed pain relief actions. Veterans use medications to control and relieve the pain on as needed basis.

The cure dimension in this outlook arises when a veteran feels there is hope that the pain will be fixed or eliminated by a future surgery, joint replacement or yet-to-be-discovered cure. In this sense, it is a more hopeful outlook compared with the two above. Also, it aligns closely with the "just get on with it" attitude in the military mindset described above, albeit one undertaken on a limited basis by moderating bodily movements, efforts and distances to avoid unwanted pain intensities and risks of further damage and future deterioration. It may also involve strengthening and toning muscles and adding mobility to joints via physiotherapy though veterans report this often does not work and can lead to more pain. It is a more pain-focused form of experiential avoidance, one directed at their pain rather than at thoughts, feelings and ideas of what it means to be a veteran with chronic pain.

Such an outlook aligns closely with the biomedical, clinical and bodily-centred model of pain management described earlier in this report. veterans having this outlook – which is common – turn to healthcare professionals (HCPs) to support them on their path to relief, fix and cure yet are often frustrated when they do because HCPs (veterans state) do not understand their military mindset and what it means to be a veteran.

In this research, 2 of the 15 veterans currently use this outlook as their dominant approach to pain management.

## Self-focused proactive pain problem-solving

In this outlook or approach, a veteran takes more and more diverse proactive, deliberative steps to improve their pain, including making changes to their environment (e.g., home, work, community) in which it arises and conditions their experience. Here, veterans attempt to actively push forward with their lives through directed efforts at wider bodily, functional, material and spatial (environmental) management and adaptation. To do so, they develop strategies, acquire equipment and make adaptations

that are consistent with their veteran self-image and especially their strong will towards self-help. Their motivation is to "get on with life" by building (and often demonstrating to others) their personal pain self-efficacy. Self-care is of course embedded in military culture and so this is a common outlook shared by many veterans and is one that is often adopted soon after leaving their service. Whilst being a form of acceptance of their pain, the acceptance is directed at controlling and solving it through personal solutions and workarounds. Pain is still central to their thoughts and experience (unlike the next and final outlook). Here too, a veteran may switch frequently between this outlook and the previous pain relief, avoidance, control and cure mentality, when they do ask for help.

A common problem with this outlook is that the cognitive and practical efforts involved can become overwhelming and exhausting. Maintaining unrealistic expectations of self-management can lead to more harm than good in the long-term. The continuous demands on thought and time needed to "solve pain" through directed activities and targeted situational improvements create more pain when efforts do not work. Pain, anxiety and frustration also arise because of the failure of others – HCPs, partners, families, charities, social workers, civilians, etc. – to understand the veteran-in-pain, to know what is needed to reduce their pain, and to help support their personal efforts.

Finally, in such an outlook, veterans tend to avoid asking for help, do not complain ("just get on with it") and can suppress their emotions, fears and feelings to avoid showing weakness to others, including other veterans (just as when in service). Such an outlook on pain management can be a lonely path. Veterans may feel worn down over time after repeated failures, pain catastrophizing, and a worsening of their pain experience. At these times, they may slip into the experiential avoidance outlook described above. Sharing experiences, tips and ideas with other veterans can help prevent this.

In this research, **most veterans** – **8 in total** - predominantly adopt this outlook in their pain approach. Given the significance of self-management, a worry is that these veterans risk becoming more debilitated over time.

# Acceptance and commitment to the pursuit of a meaningful life despite pain

The fifth and final pain outlook is where a veteran directs their thoughts and goals to a life living with yet beyond - pain. Here, they give up attempts to control, solve their pain or adapt their environment to instead pursue new activities, meanings and possibilities to form a valued, livable life. They act as if pain does not mean they are broken, functionally impaired or disabled but rather just stuck. With this perspective, a veteran commits to new actions and efforts to live a satisfying life, despite their pain. This can involve pursuing new forms of work including volunteering, new social encounters - inside or outside of the military or veteran world – and visiting new places; all undertakings that can help diffuse or distract them from their pain and reduce their suffering. One veteran explained at length how she has moved towards acceptance of her pain:

Now I accept that I haven't done this, it isn't something that I can necessarily change, but it is something I need to accept. Yeah, it is saying the difference between taking my pain personally to understanding that this is a byproduct of just what my body is. Before, I would take my inability to manage my pain quite personally I would see it as a failure. I would see it as you should be able to just suck it up and get on with this. Why can't you? I would take that quite mentally hard whereas afterwards I became able to segregate my mental health compared to my physical pain and the ownership of where that lies. So, it wasn't my fault that I was in the pain. It wasn't my inability to manage my pain - it was just pain - and I then needed to work out how to deal with it. Yeah, I think that differentiation from the experience has helped me a lot more with my mental health and that then helps me manage the physical pain. It's the biggest difference to how I hope I do not want to take my own life again.

How I see my pain is linked to how I see myself, how I respond to my own pain and how I get through day to day. It is completely different today compared with how I did this two years ago - completely different. I don't have anywhere near the same number of medical treatments I used to have, and I take half the amount of drugs that I used to. It is a huge weight off my mind.

The awareness has changed the mindset and the mindset has affected the way I manage how I deal with my pain. Because before with my pain it was more a case that I felt like it controlled me you know I felt like there was nothing I could do about it that I was almost resentful of it. It was something I deserved because I wasn't good. I took my pain personally but now. I'm like it is just a physical pain. There is no mental connection to the pain (N1F).

The challenges with this outlook or approach are that it is difficult to switch to an acceptance outlook when in intensive pain. Yet studies show that after a while of defusing and building more psychological flexibility, pain itself can diminish no matter the starting intensity. Often however, the path to acceptance and commitment only begins after reaching a low point or when giving up on the other outlooks.

This outlook or approach follows the Acceptance Commitment Therapy (ACT) model, whose use has been shown to have high positive impact amongst all people with chronic pain as well as veterans. The primary focus of the ACT model is to help a person in pain build effective and adaptive functioning within the continued experience of discomfort.

In this research, **4 veterans** have developed an acceptance and commitment outlook.

# A multiplicity of veteran pain outlooks and their evolution over time

In reality, the five outlooks are neither completely distinct from one another nor exist as definitive states of a veteran's psychology at any given time. Rather a veteran will move in and out of one of the five outlooks at different times in response to changes in their pain and to life events. Over time however, a single outlook can become more dominant. Our research suggests there is a developmental psychological pathway as veteran pain outlooks evolve. Broadly, this evolution follows the sequence of the presentation of the five outlooks above. Cognitive fusion arises at the time of the injury in service and persists through to pre-discharge and in different degrees on an ongoing basis in transition and beyond. Experiential avoidance may arise if the transition post-discharge is difficult and in response to situations where the pain limits freedoms and opportunities in civilian life. The pain relief, fix outlook is an adjustment to the reality of the pain and the need to seek professional help. Self-management, the fourth outlook, arises when a veteran feels that they alone can solve or moderate their pain (perhaps due to the [perceived] failings of the health care system to help them). Finally, the acceptance outlook emerges when the veteran becomes aware that their self-management efforts are not working or are too limiting, and a different perspective is needed.

In Table Six, we list the primary outlook of each veteran in our research along with a summary of their pain management approach, and a description of their military mindset and how it shapes their attitude to pain (where given).

# Table 6: Primary veteran outlook, pain management approach and military mindset summary

VETERAN	PRIMARY OUTLOOK	SUMMARY OF PAIN MANAGEMENT APPROACH	SUMMARY OF GIVEN MILITARY MINDSET		
N1F	Acceptance	Suicide Attempt than Acceptance. Pride when coping with pain. Trying to develop a pain immunity. Forgiveness. Not seeing pain as a failure. Pain is the experience. Not letting pain control her life.	Derived from service parents, "ingrained psyche"; Attitude of not complaining		
N2M	Cognitive Fusion	Resignation / giving up and "as-needed" medication-focused	Follow the order; not asking for help; have to be forced to go to the doctor; less deserving than others with visible injuries such as limb loss; sense of worthlessness; dealing with idiots		
N3F	Self-Focus	Balance - pacing activity with lots of medication (morphine)	Not asking for help; woe is me attitude		
N4M	Self-Focus	Medication (morphine) focus and addiction (including overdose);	Get on with it attitude		
R1M	Self-Focus	It's only pain; can fight through to an extent until it's too debilitating	"No gain no pain" ; "Train hard, fight easy"		
R2F	Acceptance	Acceptance	We are conditioned to just get on with it		
R3M	Pain Relief	Managing through failure of system through medication (tramadol)	Wishes to explain it more - but service mentality holds it back; not feeling like "bleating".		
R4M	Self-Focus	Medicaton focus and self-management	Scepticism of back problems; reluctance to go sick; malinger suspicisions; saying no to an officer still difficult		
R5M	Self-Focus	Medicaton focus and self-management by reducing activity intensity			
R6F	Experiential Avoidance	Desperation and frustration			
A1M	Self-Focus	Mobility and yoga; ibuprofen; tubigrip before activity or after pain; tries to keep fit; preparation pre-exercise; Acceptance and managing; not a lot else can do	Solider on mentality		
A2M	Acceptance	Distraction, committed action, stress avoidance,	Bypassed the pain signals; no pain, no gain; pain is an experience, learn to get on with it; didn't want to look a failure after an injury; one-upmanship		
A3F	Self-Focus	Real pain is one caused by an injury - mechanical problem; Not a mind pain. Medication focus and self- management by reducing activity intensity; doesn't see value of mind approaches; distraction doesn't help at all; there is nothing I can do other than take strong medication	Different attitude to pain in the army; Get on with it; take some pain killers; no pain, no gain. Not exercising enough. All doing is damaging enough; whinge and moan if in pain. People made to feel guilty if injured. Being in pain and injured seen as lame, or weakness. Negative connotations. Seen as weak.		
A4F	Acceptance	Emphasis on nature / the outdoors to alleviate pain			
A5M	Self-Focus	Medicaton as and when focus and self-management; tries to avoid thinking about pain; seems to ackknowledge chronicity of pain; keeps a diary but is ignored in HCP interactions; doesn't want to bore people with it.	Tracking and recording pain symptoms; quick to decide what can and cannot do - Appendix 9 - BIFF CHIT - "fit note". But can cause stigma. Managing pain whereas with GP - just doing a medication.; Wish had gone BIFF earlier;		

## Pain knowledge and veteran outlook

There is a strong correlation between the pain outlook held by a veteran and the amount of effort taken to research, learn about and understand their chronic pain, including tracking or monitoring it. Veterans having the first three outlooks are less interested in knowing their pain, its causes, patterns, factors and events. Those having the fourth outlook – self-focused pain problem-solving – are most engaged with understanding their pain, more so than those in the fifth outlook – acceptance - who desire to reduce the time they spend thinking about and controlling their pain. Making pain education and knowledge accessible and practical for all veterans must be an important feature of the Umio experience ecosystem.

# **Veterans and help-seeking**

The five veteran outlooks constitute a mixed picture of help-seeking. In the third ("pain relief") and fifth ("acceptance") outlooks, veterans proactively sought help from others. Help-seeking and accepting help involved asking for support from partners, family, friends especially other veterans, colleagues, bosses, support services and healthcare professionals. In the other three outlooks, help-seeking is rarer and only likely to occur when veterans have reached exhaustion or desperation, have run out of options or occurs when they have become particularly debilitating. Changing veteran attitudes to help-seeking must be one of the key mechanisms of the Umio experience ecosystem.

Altogether we have identified several more perceptual-cognitive (psychological) domain impacts and dimensions of veteran experience. These are shown in Appendix Two.

# Material-spatial domain findings

As described earlier in this report, the material-spatial domain consists of veteran interactions with manmade things such as products (e.g., food packaging), buildings including the home and its functional spaces such as the bathroom, stairs, and beds, vehicles including cars and tools (e.g., cutlery, DIY). Material things also include data, information, communications and media technologies (analogue and digital), medical and other product devices. The domain also covers veteran interactions within and movements through real and virtual (online) spaces and places, whether in natural or built environments.

## **Home**

Being restricted in one's ability to move around the home is one of the biggest material-spatial impacts reported by veterans in our research. Six of the 15 veterans reported challenges in climbing their stairs and either had moved (2 veterans), were in the process of moving (1), or were desperate to move (2) to a single-storey home.

The first realization was probably about four or five years after I came out of the service so you know when I say I was physically fit before I would walk my miles and miles on this knee even when it's hurting and just carry on but now I would sit and just cry like a baby at the bottom of the stairs was my kind of wake-up call but this wasn't just a little injury, it got to the point where I was actually housebound because I just could not actually get out of my property that I was in currently. I got moved to a property where I could get in and out again (N1F).

I struggle to get around now. The pain if I didn't take my medication is unbearable. I live in a house so I have to go up and down stairs but that hurts on a daily basis (**N2M**).

### **Transport**

Another commonly cited impact of pain is the limits it imposes on a veteran's ability to drive and to drive safely. This restricts their place mobility and sense of freedom.

When I hold the steering wheel - even with the best will in the world - it's a strain and then I can start to feel your hands going numb so you've got to reorder your position. There are safety issues when your hands go numb when driving and you can't feel the right instrumentation (R2F).

It got so bad once (my fatigue) that when we were driving back from visiting my daughter and I fell asleep at the wheel. My wife woke me up quickly. She always keeps an eye on me now (N4M).

I can't you know I do drive. I have my own car and but it also means I can't drive because I can't sit and kind of you know work the pedals with my feet yeah, and you know because it causes so much pain than I can't sit in that seated position and I need to be in so again. Driving can make the pain worse as well is that when there's when there's a flare up or or just driving normally yeah, that's That's when I you know so in The Thick of and you know the worst kind of pain I can't use my car um okay. Um so and the other any other impacts let me put the connection (A3F).

Then again, the use of and access to public transport can present problems too.

Public transport is a bitch with chronic pain. It's everything. Getting to the stop, getting on the bus. The bus is always packed so you're not going to get a seat. Same with the trains. Public transport in general is an absolute nightmare (R3M).

#### **Travel**

Other veterans reported how they could no longer go on holiday.

I can't go on holidays with my wife because I can't walk far so it's pointless me going, so I haven't been away for years (N4M).

#### **Environment**

Navigating tricky outdoor environments can be a challenge for veterans with hip, knee or ankle pain as it can lead to a loss of balance and falls.

I need to be cautious and take my time. Walking on cobbles and stuff like that - I will take more care because I don't want to twist my hip or twist my ankle or anything like that. So I will just slow down and be more mindful of what I am walking on (A1M).

Altogether we have identified several material-spatial domain impacts and dimensions of veteran real experience. These are shown in Appendix Two.

# Social-cultural domain findings

As described above, the social-cultural domain in the model of veteran real experience consists of their interactions with other veterans, with their partners and families, with friends, in communities and social groups as well as with human actors or agents within organizations of all types. The latter include interactions with professional health care and pain specialist agents in physical or virtual clinical and care practices. In the research, impacts of chronic pain spanned all these entities or elements in veteran experience. We briefly explain each.

## **Family**

Veteran interactions with their partners and families, especially children and grandchildren suffer because of their pain. Five veterans mentioned the struggles they have had with their partners due to their anger

and frustrations. In three cases, this has led to relationship breakdown and divorce. Other veterans have been unable to form relationships since leaving the service, in large part due to their chronic pain. Six veterans talked about the sense of loss they experienced because they were unable to pick up, carry or play with their children. One spoke of the envy he feels of other Dads who are able to do so.

I can't do anything with my grandkids at all I can't walk because of the pain and obviously they want to be picked up or something, but I can't pick them up (**N4M**).

My daughter was about two to three years old when I first really developed the knee pain. It was so bad I couldn't risk carrying her upstairs to put her to bed. I had to crawl up the stairs at the time or I would have to use the banister with one hand on that and one hand on the baby. I didn't feel safe doing it so I stopped. There's certain other things, like playing football with my son. Things like that you miss out on (**R4M**).

I find it hard to sleep at night as well because sometimes I get into the position where I have pain so have to move into different positions. That's why I can't have the same bed as my wife - I have to have a different bedroom because I will keep the wife awake with me (N4M).

#### Friends and social isolation

A common impact theme too was social isolation, of being housebound and of losing touch with friends, including fellow veterans. One explained how she could no longer go out and frequently had to postpone attending social events and engagements with her friends because of her pain.

I can't physically get out and because am taking a lot of medication, it wouldn't be a very good idea to have an alcoholic drink. So there's no point in trying to socialise as such when am in pain. There's been lots of occasions where I've organised to go out and meet friends or do something for the weekend, and then at last-minute notice, I've had to cancel due to a flare-up. On the plus side, my friends have been around for a long amount of time and they know that my injury comes and goes. (A3F).

#### Work

In respect of work, only 5 of the 15 veterans interviewed are in full-time work, 2 do voluntary work, and 1 is retired – leaving 8 unemployed. Not all draw a service pension and 2 reported they were unsure if they were entitled to one.

Some days. I struggle to string sentences together - I can't even talk today - so working at the moment is just totally out of a question because I'm just not in a fit state to go (R6F).

Others reported challenges at work itself and the need to change jobs or shift their role at work because of their pain.

I have problems sleeping which is a problem because of my work as a (anonymised). It's kind of important that I do sleep prior to work. There's a lot of walking involved in my work as well as concentration. But also long sedentary periods sat on my bum. But then I have get up and I struggle to change locations. Sometimes I am limping from end to the other (R1M).

#### **Healthcare**

Nearly all veterans in the research reported frustrations at dealing with the NHS, whether GPs, pain specialists and clinics, surgeons and surgical outcomes or mental health practitioners and services. Yet their experiences tend to be hit and miss rather than a complete failure as some reported positive interactions.

I have a real problem with the kind of backward thinking in organisations like the NHS that try to offer something. They know I am a veteran, but they don't give a f\*\*k. It seems that nobody gives a damn. You're just treated like everybody else and no one seems to give a hoot. I feel I am treated like a third-class citizen sometimes. It's quite bad. I mean the treatment I have had has been horrific. (R3M)

Table Seven summarises each veteran's brief reports of their civilian NHS experience.

Table 7: Brief summary of each veteran's civilian healthcare experience

VETERAN	SUMMARY OF HEALTH CARE EXPERIENCE	
N1F	No help for mental health offered but doesn't want to be a problem; more deserving attitude; undergoing CBT now but not for pain	
N2M	Very Negative; Physio has made things worse; GP not helping nor pain specialists	
N3F	Positive; "Amazing" GP; mixed pain clinic experience as civilians also on course; Mental health services good	
N4M	Cannot get any surgery	
R1M	Positive but went private	
R2F	Poor- anti-depressants led to suicidal feelings; "hit and miss"; physio was "no use"	
R3M	Very negative; Physio don't know what they are doing; surgery with no scans; don't care if you're a veteran; painclinic referral but no follow-up	
R4M	Dificult to talk about it; don't look at the cause; private clinic had more time and better service; long NHS waiting lists; physio made no difference	
R5M	More positive than others; private care through the NHS	
R6F	Fairy good apart from waiting times; positive about OpCourage; cant get hold of medical notes from military; NHSservices don't really undertand how think and feel	
A1M	Physio not any good; GPs slow to act	
A2M	Negative so went into it himself	
A3F	Under treatment of pain management clinic but long waiting list; big gap in Covid; GPs and HCPs don't se veterans any differently to civilians; tried a range of alt. therapies	
A4F		
A5M	Sees consultant rheumatologist; Advanced GP trying to deal with it all; MSK specialist help but not well-joined up; GP not paying attention to pain diaries;	

In general, veterans in the study feel that healthcare professionals fail to live up their promise and that they do not understand the veteran mindset. Further, their actions to address or alleviate pain do not always work, leaving veterans feeling more desperate and on a downward trajectory. This frustration is particularly felt after surgery. Almost half the sample of veterans (7) reported they had had multiple surgeries as civilians, yet their pain had not improved, or the problem fixed. A few (4) were unable to obtain a diagnosis of their more widespread chronic pain that is not linked to a specific bodily site. They felt completely stuck as to what to do to achieve progress.

When seeking help from pain specialists in clinics, the few (3) that had used them came away disappointed with their experience and impact. They felt they were too bodily, medication and physiologically-focused and did not take a whole person-in-pain view. Attending mixed civilian-veteran group clinics was also an unsatisfying experience. Those running the group sessions do not appreciate that veterans have differing, yet quite specific, beliefs around pain management, which as we described above is largely self-management focused. Further, access to pain clinics is limited. Not all local hospitals have them, and some clinics are so small that all they can offer is medication and a physiotherapy referral.

**Veteran Charities** 

As well as the direct veteran research, we reviewed 250 veteran charities. We found none that offered any form of defined support for veterans experiencing chronic pain. Veterans in our research had not approached them for help due to their "not seeking help mentality", because they felt they were undeserving of help, or did not feel the charities were able to help. There was some scepticism too concerning the PTSD and mental health services offered by many veteran charities and outreach groups. One veteran spoke of his sense that some veterans were "over-egging" their PTSD in order to obtain help and attention. Whilst the major charities were good at helping with material and financial support, and some help with training and education too, veterans in the research were less amenable to seeking help for mental and physical health problems. Again, there was a sense did not deserve their support in the first place.

#### **Other Veteran interactions**

Finally, veterans in our research all commented on the positive value of maintaining veteran interactions and the usefulness of sharing pain ideas, tips and experiences with one another, whether virtually online or in-person. The younger veterans in the sample found their peers more amenable to talking about their mental health and all veterans felt that pain-focused discussions can be a useful lever to open up those reluctant to discuss their mental health problems. The role of humour and banter was seen as important as long as they do not distract from the primary purpose of attaining some practical useful action from veteran peer engagements.

Altogether we have identified several social-cultural domain impacts and dimensions of veteran real experience. These are shown in Appendix Two.

## Assemblages of veteran chronic pain experience

Using the qualitative insights into veteran real experience gained in this study and from past Umio chronic pain research, we can build a model consisting of tentative contingent assemblages of different states, qualities and experiences of veteran chronic pain. In each assemblage, we can make a rough estimate of the number of veterans with chronic pain belonging to that assemblage. Further, as mentioned above when introducing assemblages, this also serves as a model of the evolution and transition of different qualities and expressions of veteran experience over time.

Table 8 shows the estimated distribution of veterans in each of six assemblages – At Risk, Worsening, Chaotic, Emerging, Building and Sustaining. In the table you will notice the greatest percentage is those whose experience with pain is worsening. This is due to the limitations of the current pain management model and services in the NHS and the frustrations and failings that veterans continue to experience when adopting the predominant self-management outlook and approach to their pain.

Figures 9 and 10 summarise the key dimensions of each interactional domain in each assemblage. Using this way of seeing differences in real experiences with pain along with the developmental paths of decline and recovery, assemblage thinking can inform the design of novel veteran strategy, policy and resources. The assemblage way of thinking is central to the Umio experience ecosystem platform.

Table 8: Distribution of 1.05 million UK veteran chronic pain population in assemblages of real experience

	At Risk	Worsening	Chaotic	Emerging	Building	Sustaining	Total
Per Cent	25%	35%	20%	15%	5%	5%	100%
Number	262k	367k	210k	157k	52k	52k	1.05m

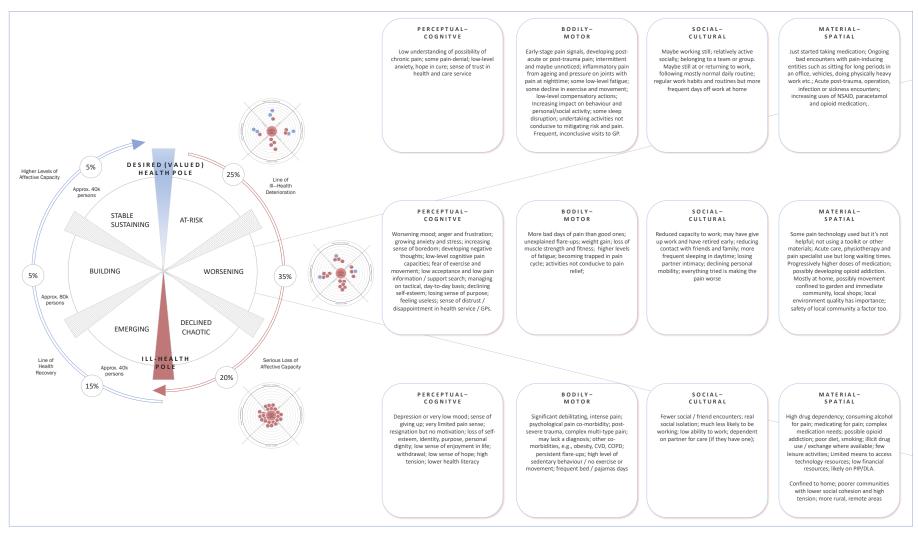


Figure 9: Assemblages of veteran real experience on the line of deterioration (at risk to chaotic)

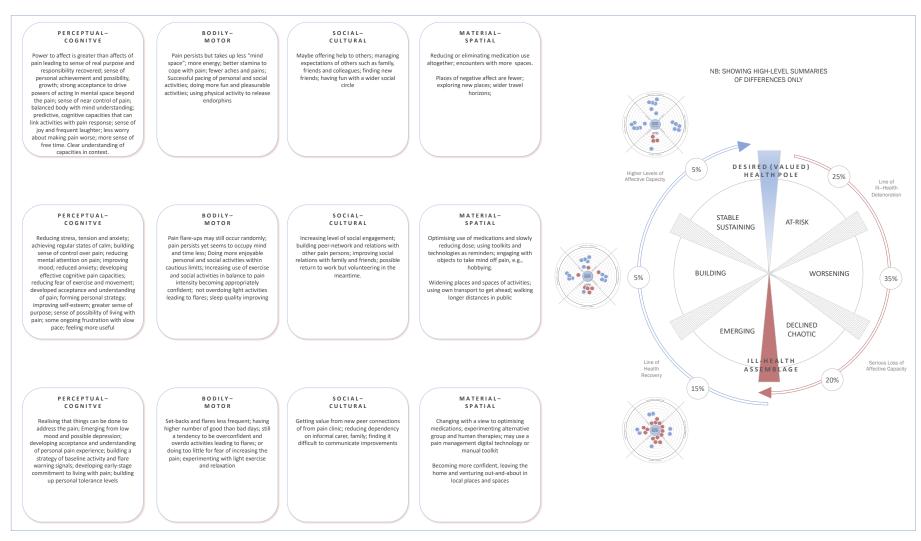


Figure 10: Assemblages of veteran real experience on the line of recovery (emergent to sustaining a valued life)

#### Discussion and recommendations

The novel concepts, primary qualitative and secondary desk research described in this report together define an ecosystem scope, purpose, design, method and rationale for transforming veteran with pain experience, and support and specialist practices in the UK (and elsewhere). This spans several "shift dimensions" depicted in Table 9.

#### Such a transformation:

- Shifts thinking on veteran chronic pain model from a clinical, biomedical to a whole ("holistic") experiential model.
- Improves all veteran stakeholder pain knowledge, coordination and creation across the whole ecosystem.
- Advocates for veterans living with chronic pain by making chronic pain visible amongst the veteran and wider stakeholder ecosystem.
- Addresses veteran reluctance to raise their suffering and seek help; and design peer-peer mechanisms to overcome their desires and tendencies to self-manage.
- Reveals differences in veteran outlook and experience with chronic pain (coping, capacities, resources), the transitions or movements in those experiences, and the forces driving them.
- Builds new insights into the real nature of veteran experiences with their pain, not just quantities in a black box of epidemiological data, but also insights into the everyday social, affective and material contours and limitations of their lives
- Goes beyond individual health and health care to wider interactions or repertoires of social, cultural, material, environmental, spatial and affective elements, events, practices and relations that inhibit or sustain veteran wellbeing as a distinctive mode of social care.
- Moves from a linear fragmented service and support model to an experience ecosystem / meshwork model centred on veteran and veteran stakeholder real experience.
- Ensures inclusivity of all veterans female, service ranks, ethnicities, young, old and their diverse experiences and struggles with chronic pain

In this transformation, the locus of veteran pain knowledge creation, innovation and engagement shifts to an open focal relational experience ecosystem supporting digitalized as well as physical interactive experiences. Here, experience-centric value creation no longer happens within a single enterprise or practice (e.g., charity, pain clinic) interacting with a veteran but rather occurs within an experience ecosystem of multiple connected enterprises, settings and stakeholders – veteran charities, pain clinics, community outreach groups, social care, family members, community organisations, sports clubs and gyms and other stakeholders.

In a veteran experience ecosystem, impact accrues from the emergent positive experiences of veterans accessing insights, obtaining knowledge, building an understanding of acceptance, committing to action, helping others and receiving care, support and services in events and flows of their lived journeys as well as in those of supporting and enabling stakeholders.

Value is co-created from the experienced impacts of the positive affects (sensations and capacities) arising in veterans, from the positive affects arising in the experience of veteran family members and from the positive affects arising in the experience and impacts of supporting stakeholder actors.

Table 9: Dimensions in the Umio shift in veteran pain approach, management and action

Current Veteran with Pain model	Umio Transformation of Pain in Real Experience
Chronic pain relief, fix, cure	Accept and commit to making a liveable life with pain
Professional care actors	Distributed, democratised engagement with diverse stakeholders
Clinical reasoning, intellectual analytical thinking	Whole intuitional sympathetic experience thinking
Individual person (veteran)	Assemblages of collective content and capacities of real experience
States of experience	Events, transitions and movements in (assemblages of) real experience
A veteran's needs and resources	A veteran's capacities for affecting their real experience with pain
Bodily-motor focus of pain (pain site)	Holistic interactional social-cultural, material-spatial, bodily-motor, cognitive-perceptual experience focus
Pain magnitude – intensity – score	Pain impacts in real experience and real experience impacts in pain
Pain as secondary to a bodily injury, damage or trauma	Pain as secondary and primary (independent of trauma, damage or injury)
Pain as static and intermittent having similar content and expression	Pain as a rhythm or flow having difference in real experience
Pain as having limits of extent in bodily site	Pain as becoming more chronic, expansive / whole and primary
Pain as in the brain (brain reduction)	Pain as in whole real experience
Self-management focus	Collective supportive peer-creation in self-management
Health care	Expansive (health and) wellbeing (capacity) creation
Linear health care pathways and service design	Define experience engagements and flows of creation in events of experience
Cost-reduction and standards of care	Valued positive affect creation and ecosystem distribution
Beneficiary actor (veteran) focus	Multi-agential stakeholder experience focus centred on veterans, partners and families
Local neighbourhood – community focus of creation	Local and non-spatially defined creation - innovation
Planning-response to change in pain (health state)	Sense-anticipation of events in real experience
Outcomes	Impacts of outcomes in real experience
User-centred design	Real-experience flow-centred creation
Health and social care system	Experience ecosystems centred on a focal context (e.g., veterans with chronic pain)

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## Appendix One - Qualitative interview / discussion guide

#### INTRODUCTIONS

Thank the respondent.

Ask how they are today.

#### **ABOUT THE STUDY**

#### 5 minutes

This research is the first phase in a project sponsored by the Office of Veteran Affairs in the UK Cabinet Office for which my group has a won a grant. This is to fund the research and development of a veteran chronic pain ecosystem that helps veterans and their families to better know their pain, find services, connect stakeholders, get help, and provide support to one another.

The purpose of our discussion today is to learn about your personal experience of living with chronic pain as a veteran. In doing so, this will provide vital inputs to the design of the new pain system for veterans.

#### CONFIDENTIALITY

#### 1 minute

Before we begin, let me reassure you that this interview is subject to all industry codes of conduct and therefore all information provided will be treated in the strictest confidence. All information you share will only be reported in an anonymous form.

I would like to point out that you may withdraw from the interview at any time.

Does that sound OK? Do you have any questions?

#### **RECORDING**

#### 30 seconds

I would like to audio-record the interview. This will only be used by for note-taking purposes. After the interviews are complete, they will be deleted within 45 days of today or sooner.

#### THEIR SERVICE EXPERIENCE IN RELATION TO PAIN

First off all, can you tell me a little about your service.

When did you enter - leave?

Which branch of the military were you with?

When did you sign-off / come out?

#### **THEIR PAIN**

#### 5 minutes (be sensitive and extend if needed)

Next, I would like to chat about your pain.

Could you tell me a little more about your pain? In particular,

- o When it came about?
- o How it came about? Did your pain arise from your service?
- Location

- o Intensity / severity
- Frequency
- o What has changed over time?

Have you a diagnosis of your pain?

Do you have any other forms of chronic pain? Headaches, IBS, general pains over the body?

Do you have other physical health conditions?

Are you diagnosed with PTSD? Or other mental health conditions?

#### **MEDICATIONS**

Do you take medications for your pain?

Do you take medications according to a routine or at set times? Or randomly?

Do you numb your pain in other ways?

How do you feel about taking medications for your pain? Probe for addiction avoidance.

#### PAIN IMPACTS IN REAL EXPERIENCE

Next, I would like to understand how your pain impacts your life.

Pain stories?

Could you describe how your pain impacts your life? If a lot or some, probe for areas:

Impairment

Activity Limitation

Participation Restriction

- Movement, e.g., walking, running, standing, bending, sitting etc.
- Activities, e.g., sports, gardening, DIY, driving.
- Self-Care, e.g., washing, showering, bathing, etc.
- Sleep
- Work (finding work, staying in work, etc.)
- Family
- Friends
- Outdoors activities
- Attention focus such as reading or watching TV
- Other things you what like to do / what matters to you

Are you still able to experience new things despite the pain?

#### **PAIN AFFECTS**

What feelings does your pain create in you? How does it affect your state of mind or wellbeing?

How do you think about your pain – about why you manage it or approach it or think about it the way you do? I am going to throw some words up here:

- Guilt
- Pride
- Loss

- Badge of Honour
- Sadness
- Humor
- Identity
- Acceptance
- Lucky

As a veteran, do you think you think differently about your pain compared with non-veterans?

Does experiencing pain have any meaning to you in relation to your service? Whether positive or negative? Or none at all?

#### **CIVILIAN TRANSITION**

How has your transition to civilian life been?

Probe for:

- Work
- Housing-home
- Relationships and family
- Mental health
- Mobility
- Veteran relationships

#### **KNOWING YOUR PAIN**

How well do you think you know your pain? What would you like to know more?

Have you investigated the cause / condition with the view to seeking possible treatment or just to learn more about it?

Next, I would like to understand what you think produces your pain? Such as episodes, flare-ups? What makes it worse?

If they don't know, probe for areas:

- Worry
- Stress
- Fatigue
- Aspects of the Weather

Would you like to be able to better predict your pain?

#### **GETTING HELP FOR YOUR PAIN**

Next, I would like to understand what if any help you've sought for your pain?

Asking for help? Why it is hard for veterans to ask for help?

If yes, what kinds of help?

Do you ask for and obtain help from your family and friends?

If yes, how does it help?

If no, why not?

Do you regularly visit a doctor or other healthcare professional for your pain?

If yes, does this help?

If no, why not?

Have you tried any non-medication therapy types: CBT, ACT, Group, Mindfulness, Physiotherapy, etc.

If yes, was this helpful?

If no, why not?

Have you obtained support – help for your PTSD? Was this help combined with your pain?

Probe for healthcare, pain specialisms, GP, Which health care settings?

How does being a veteran affect the help you get?

How does being a veteran affect what you think about the help you get?

Have you sought help from the "military family?" Veteran charities or services?

Have you sought help from talking to other veterans?

Veteran Inspiration? Service people?

#### **TECHNOLOGIES USED AND PAIN**

Do you use any technologies for your pain?

Probe for digital technologies such as apps, wearables, websites, etc.

#### **GETTING OTHERS TO UNDERSTAND YOUR PAIN**

Do other people understand your particular experience with pain? If not, what would help you to help them better understand? Probe for:

- Healthcare professionals
- Family
- Friends
- Colleagues
- Employers
- Institutional Stakeholders (Assessors)

#### FINDING ACCEPTANCE

Have you found some sort of acceptance with your pain?

(If yes – how have they done this

If no, are they still trying to control or find a cure?)

#### WHAT DOES A MEANINGFUL LIFE MEAN TO YOU MEAN NOW?

Open question

#### **HELPING OTHER VETERANS WITH PAIN**

Open question

#### HELPING THE COMMUNITY TO HELP YOUR PAIN

#### Open question

## WHAT'S NEXT WITH YOUR PAIN? STATE OF ACCEPTANCE – TOLERANCE – CONTROL – AGEING AND PAIN

What would you say is your state of acceptance of your pain? Are you resigned to your pain?

If resigned to your pain, what could make life living with it better?

Ageing and pain?

What would you like to do more of?

What help would you like?

What information would you like?

#### **CONCLUSION**

#### 2 minutes

- 1. Is there anything important I missed or anything else you would like to add?
- 2. Do you have any final questions?
- 3. Have you any ideas or inputs you would like to share further?

#### WRAP UP AND THANKS

# Appendix Two – Dimensions of chronic pain impacts in the real experience of veterans

## **Bodily-Motor domain**

	0 11./01
Body Size	Overweight/Obese
	Underweight  Muscle Tone
	Muscle Forne  Muscle Srength
	Muscle Endurance
	Joint Mobility
Physiological - Motor	Proprioception
	Other Sensory Functions Related to Temperature and Other Stimuli
	Sexual Functions
	Touch
	Balance (Vestibular)
	Voluntary Movement
	Flare-ups
Changes in Pain	Persistence
	Periods of Calm
	Blind
Disability	Deafness
,	Wheelchair
	Crutches
	Sleep
Sleep-Rest	Rest
	Calm
	Personal Health
	Toileting
	Bathing
Personal Care	Showering
	Personal Hygiene
	Dressing / Undressing Clothing
	Putting on - Removing Shoes
	Walking
	Running / Jogging
	Bending
	Lying Down
	Standing
	Sitting
Independent Motor-Movement-Exercise	Exercising
	Massage
	Physiotherapy
	Lifting-Carrying Objects
	Changing-Staying in Position
	Individual Sport Participation
	<u>·</u>

## **Material-Spatial domain**

Sheltered Housing  Social Housing  Care Homes  Housework  Home Bathing  Home Sleeping (Facilities)  Home Access (Exterior)  Home Access (Interior)  Home Adaptation for Mobility  Home Adaptation for Rest  Home Security  Home Heating and Insulation  Home DIY Repairs - Maintenance  Gardening  Allotment  Landscaping/Redesign  Garden Clearance  Local Gradients - Levels  Local Gradients - Levels  Natural Environment and Climate  Natural Environment, Parks, Woodlands, etc	
Care Homes Housework Home Bathing Home Sleeping (Facilities) Home Access (Exterior) Home Access (Interior) Home Adaptation for Mobility Home Adaptation for Rest Home Security Home Heating and Insulation Home DIY Repairs - Maintenance Gardening Allotment Landscaping/Redesign Garden Clearance Local Gradients - Levels Distances Safety Weather-Climate Natural Environment and Climate	
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Local Neighborhood  Distances  Safety  Weather-Climate  Natural Environment and Climate  Seasons	
Safety Weather-Climate Natural Environment and Climate Seasons	
Weather-Climate Natural Environment and Climate Seasons	
Natural Environment and Climate Seasons	
Natural Environment, Parks, Woodlands, etc	
Cycling	
Transport-Movement (Material Things)  Driving	
Public Transport	
Mobility Equipment	
Drug Addiction	
Substance Use Substance Addiction / Misuse	
Nicotine Addiction / Misuse	
Alcohol Addiction / Misuse	
Healthy Food	
Food Packaging	
Material (Food and Food Packaging) Food Consumption / Diet	
Cooking - Preparing Food	
Recycling-Reuse	
Social Media	
Material (Technology) Assistive-Adaptive Technologies	
Digital Pain Apps	
Disability Benefits	
Welfare Benefits	
Pension and War Compensation  Material (Finances)	
Household Finances	
Cost of Living	
Debt	·
Sports Equipment	
Weights	
Material (Equipment) Exercise Equipment	
Sports Shoes	
Sports Clothing / Gear	
Clothing	
Shoes	
Material (Clothing) Running - Exercise Clothing	
Running- Exercise Shoes	
Cleaning Clothes	

## Social-Cultural domain (part 1)

	Layperson Interactions
Social (Everday Interactions)	Partner Interactions
, , , , , , , , , , , , , , , , , , , ,	Child Interactions
	Pets (Dogs especially)
	Peer Relationships
	Veteran Relationships
Social (Relationships)	Family Relationships
	Sex/Intimate Relationships
	Separation - Divorce
	Taking up a New Team Sport
Sports	Becoming a Physical Trainer
	Sporting Events
	Respite Holidays
	Challenge Holidays
Leisure Travel	Activity Holidays
	Days Out
	Concerts / Gigs
	Theatre
Cultural Events (MeetUps)	Festivals
	Film Nights
0.1.6.114	Group Walking
Outdoor Social Activities	Group Cycling
	Group Running (Park Runs etc.)
Outdoor Social Events	Garden Parties
	Adult Education
	Becoming a Trainer / Teacher
Education	Learning a Language
	Learning Maths-English
	Social Isolation
Social (Loneliness)	Making Friends
Jociai (Lonenness)	Dating
	New Relationships
	Job Search
	Job Retention
	Job Leaving
	Start a Business
	Business Loan
	Grow a Business
	Apprenticeship
Work (Paid)	Skill Sourcing - Development
	Skill Exchange
	Vocational Training
	Return to Work
	Train Others
	Boss Interactions
	Colleague Interactions

## Social-Cultural domain (part 2)

	For Other Individual Veterans
Walada (Valantana)	For Veteran Organsations
Work (Voluntary)	For Individual Non-Veterans
	Local Environment
	Fundraise
Charita	Sponsorship
Charity —	Set-up a Charity
	Talking About - Explaining Pain to Other Veterans
	Veteran Friendships
Veteran (Relationships)	Veteran Meet-Ups
	Veteran Connections
	Veteran Values
	Goals
	Religion
(-luin-Cultum- Saniata	Ethnicity
'alues in Culture-Society	Gender
	Sexuality
_	Healthcare View of Pain
	Carer Interaction
	Assessor Interactions
Social Care	Social Worker Interaction
	Home Care
	Community Centres
	Pain Experience
Usalah Cara (Chahanana)	PainTherapies (non-Drug)
Health Care (Statutory)	Pain Innovation
	Pain Technologies

## **Perceptual-cognitive domain**

	Acceptance
D	Self-compassion
Perceptual	Setting Goals
	Catastrophising
	Temperament
	Stress
Mental Health	Anxiety
	Depression
	Grief
	Pain Memory
	Focus - Attention
	Motivation
	Energy
	Problem-Solving
Comition (Bouch device)	Self-Efficacy
Cognitive (Psychological)	Pain Acceptance
	Defusion
	Mindfulness
	Personal Growth-Learning
	PTSD
	Grief
	Problem-Solving
Cognitive (Learning-Memory)	Learning a New Skill
	Developing Brain Skills - Memory

## **About Umio**

Umio Health Ecosystem Value Design<sup>®</sup> is built on a radical philosophy of real lived experience, challenges status quo thinking, captures original insights, and facilitates advanced learning, design and value-creation ... in any health and wider social context.

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