COMPLEMENTARY AND ALTERNATIVE MEDICINE SURVEY

Summary Report

March 2024

VERSUS ARTHRITIS

Introduction

The use of complementary and alternative medicine (CAM) for the self-management of rheumatic and musculoskeletal conditions continues to grow, though clinical evidence for the effectiveness of most treatments and therapies remains relatively weak or understudied.

This lack of robust evidence is just one of many factors that make the rapidly expanding marketplace for CAM treatments and therapies difficult to navigate for consumers and patients. The field is unevenly regulated; there is little data around supplement safety and interaction; promotional hype and commercial bluster are rarely challenged or held to account; primary and secondary healthcare practitioners are minimally engaged in discussion and decision-making around CAM interventions; and the voices of consumers and patients are little heard in debates around the effectiveness of various treatments and therapies.

Versus Arthritis has long been aware of the importance of self-management for people living with arthritis. From our helpline, online community, social media, local engagement, and self-management programmes, we know that growing numbers of people living with arthritis (particularly those awaiting diagnosis or surgery, or with symptoms that do not respond to disease-modifying drugs or biologics) use CAM and other forms of self-management for chronic joint pain, inflammation, stiffness, fatigue and other symptoms.

Yet we know little about the pathways to engagement with self-management, the advice and information that is relied upon, and, most importantly, the perceived effectiveness of specific treatments and therapies.

With these questions in mind, the Health Information team sent an online survey, via Smart Survey, to Versus Arthritis' supporter network in January 2024. This survey set out to identify all types of self-management used by people with lived experience of arthritis, including exercise, supplements, herbal remedies, diets, devices, and physical and psychological therapies.

Survey respondents were asked how they rated the effectiveness of these treatments; what symptoms they were seeking to relieve; the sources of information that they had recourse to; and the extent to which health professionals had participated in discussions around self-management.

Finally, respondents were given the opportunity to rate a number of features that might help improve our current health information on complementary and alternative treatments and therapies.

The survey received 2,802 responses from people with lived experience of arthritis or an MSK condition. The majority of respondents (68%) were aged between 55 and 79 years of age, and 78% were women.

74%
of respondents had osteoarthritis

40%
had some form of inflammatory arthritis

18%
had a bone condition such as osteoporosis

As these figures indicate, a significant number of respondents reported that they were managing multiple conditions.

Key Statistics

87%
of respondents have used at least one form of self-management.

81%
of respondents said pain was the principal driver to self-management, with stiffness, inflammation and fatigue accounting for much of the remainder.

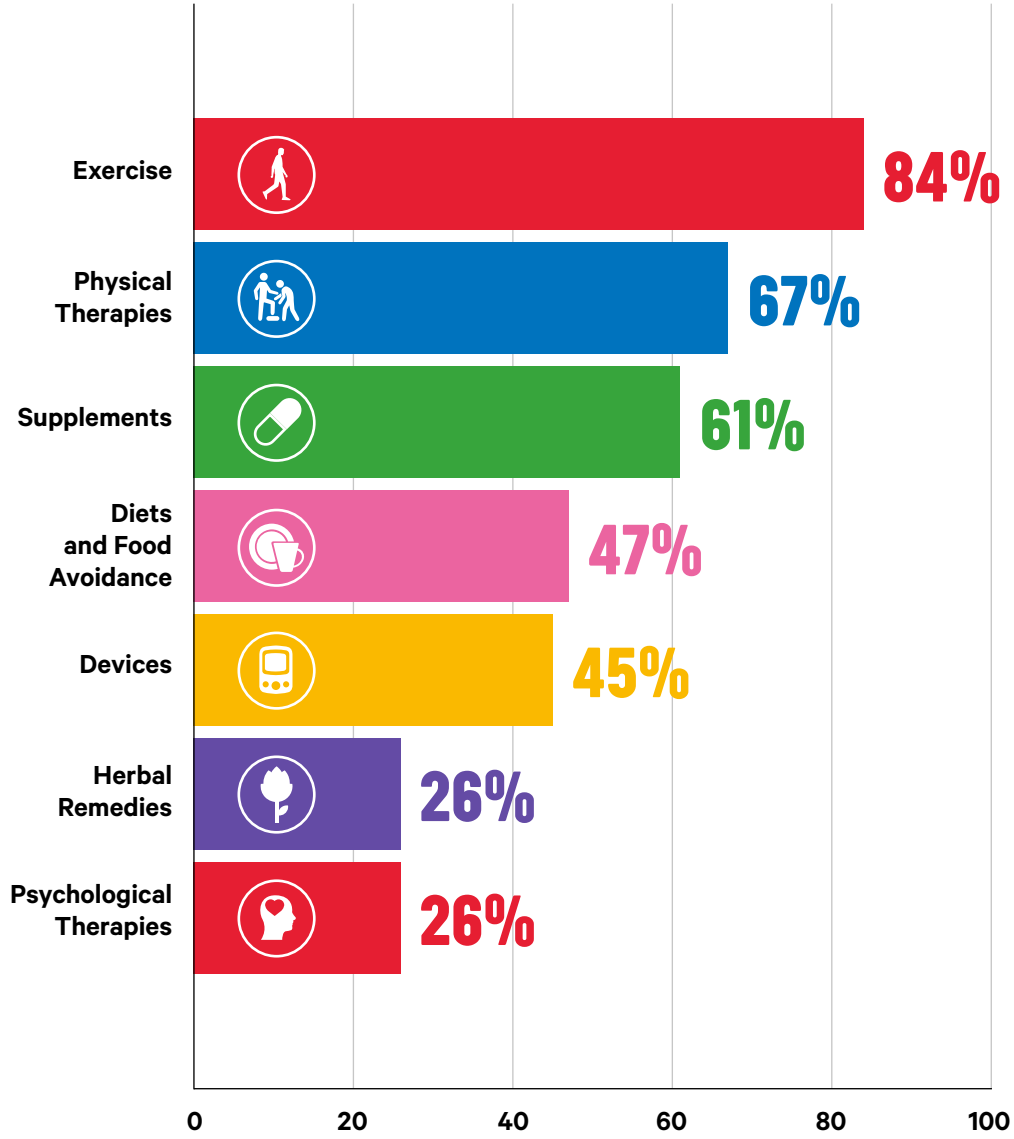
35%
of respondents came to self-management through personal recommendation.

32%
of respondents said that they didn't 'know enough' about treatments and therapies, making lack of knowledge the greatest barrier to self-management.

17%
of respondents who had not used a form of self-management felt excluded by cost.

LESS THAN 10%
of respondents accessed alternative therapies or self-management programmes via the NHS.

Percentage of Versus Arthritis survey respondents that have used self-management



EXERCISE

84%
of respondents found that exercise was the single most popular form of self-management used.

Approximately **15%** of respondents reported being unable to exercise due to pain or fatigue, and significant numbers reported a concern that exercise might make their existing symptoms worse. Others pointed to a lack of local facilities/inability to travel as a barrier to exercise.

49%
of those using exercise did so on the recommendation of health professionals.

STRETCHING, SWIMMING AND WALKING
ranked as both the most used and most effective forms of exercise for symptom relief.

83%
found stretching effective in some degree,
78%
swimming, and
77%
walking.

75%
of those that used Versus Arthritis' Let's Move classes experienced some benefit.

"Exercise has been my healing."

"Joining a local gym has been the biggest and most rewarding thing I have done regarding my arthritis."

"Walking has been the best medicine."

"Taking positive steps to increase the amount and intensity of exercise under expert guidance has had a hugely beneficial impact on my flexibility, and on my pain levels."

"Swimming is brilliant but rural pool facilities are not good."

PHYSICAL THERAPIES

67%
of respondents used at least one form of physical therapy, making it the second most popular form of self-management.

55%
experienced some benefit from acupuncture. Osteopathy, chiropractic and reflexology were similarly rated for effectiveness.

47%
of all respondents used physical therapies on the recommendation of health professionals.

Approximately
40% used massage
40% acupuncture
22% hydrotherapy

HYDROTHERAPY AND MASSAGE

were the stand-out physical therapies: hydrotherapy was found effective to some degree by 76%, massage by 75%. A third of all hydrotherapy users (34%) thought it was highly effective, the highest rating given to any treatment or therapy in this survey.

Some of the other physical therapies used for self-management include the Alexander technique, cranial sacral therapy, cryochambers, oxygen therapy, lymphatic drainage and Reiki.

"The chiropractic treatment I had over the years has enabled me to continue my nursing career, when I was told I wouldn't be able to carry on working as a staff nurse."

"Hydrotherapy and acupuncture worked, but due to costs these aren't really an option."

"When you are on benefits, these therapies are totally unaffordable at £50+ per hour/session."

SUPPLEMENTS

61%
of respondents have used supplements. Vitamins, fish oil and glucosamine ranked as the most used.

64%
of these respondents found that vitamins (A, B, C, D or multi) were to some extent effective.

Supplements were also used for **RELIEF FROM EFFECTS OF BIOLOGICS** (e.g., biotin for hair loss, and l-lysine for cold sores), and as alternative to over-the-counter nonsteroidal anti-inflammatories such as ibuprofen.

58%
thought they benefited in some degree from taking fish oil.

THREE VERY POPULAR ARTHRITIS SUPPLEMENTS PERFORMED LESS WELL IN TERMS OF PERCEIVED BENEFIT.

28% of respondents found MSM (Methylsulfonylmethane) in any degree effective. Green-lipped mussel was found to be effective by 31%, and collagen by 38%.

GLUCOSAMINE WAS REPORTED EFFECTIVE by 49%, and chondroitin by 38%.

"The rheumatologist recommended glucosamine, fish oil and ginger and keeping active. He was right. I can still manage with very few pain killers."

"I've wasted a lot of money trying different supplements, nothing helps."

"I find it difficult to be sure that supplements etc will not affect other medication for a heart problem."

DIET AND FOOD AVOIDANCE

47%

of respondents used some form of diet or food avoidance, and approximately a third (34%) did so on the recommendation of a health professional.

ALMOST A THIRD

of respondents (32%) reported having tried either a plant-based or vegetarian diet, approximately half (55% and 52% respectively) finding some improvement in their symptoms.

EXPERIMENTATION WITH 'ANTI-INFLAMMATORY FOODS'

(berries, avocado, walnuts, olive oil, fermented food, green veg and oily fish) was quite commonly reported.

THE MEDITERRANEAN DIET RANKED HIGHEST IN POPULARITY

having been followed by 33% of respondents. The Mediterranean diet was rated as effective to some degree by 75% of users.

ONE IN FOUR

respondents (26%) said they had experimented with food avoidance. 74% reported some benefit, with a significant minority rating food avoidance as highly effective. Foods principally avoided were sugar, red meat, alcohol, tomatoes and other nightshade vegetables.

As well as being used to RELIEVE PAIN, INFLAMMATION AND FATIGUE, these and other diets have been used for weight loss and for diabetes.

"I chatted with my consultant about complementary therapies and dietary changes. His response was very much – they don't work but try them if you want to."

"Refined sugar definitely affects my pain and stiffness so I try to steer clear of it as much as possible."

"Tried cutting out all the known triggers for inflammation and arthritis, but nothing helped."

DEVICES

THE USE OF DEVICES SUCH AS TENS MACHINE AND HEAT PADS

is widespread among people managing arthritis and MSK conditions, with 45% of survey respondents reporting having used at least one type of device.

ALMOST A THIRD

(32%) have experimented with a TENS machine, and 63% of those reported some positive effect.

In around 45% of cases, devices were used on the recommendation of a healthcare professional.

THE MOST EFFECTIVE TYPE OF DEVICE ACCORDING TO RESPONDENTS IS AN INFRARED HEAT PAD/PANEL.

Used by 21% of respondents, infrared heat provided some degree of relief to 77%. A significant proportion (24%) found infrared heat to be highly effective.

Lesser-used devices, including

BIOFEEDBACK, LIGHT THERAPY AND CIRCULATION BOOSTERS,

were all poorly rated with less than half reporting any positive benefit.

"Microwavable heat packs 12-20 times a day, couldn't live without them."

"The TENS machine helps take the pain away and helps me do more things and for longer."

HERBAL MEDICINES

ONE IN FOUR of respondents (26%) say that they have used at least one herbal medicine, nearly half (45%) reporting that they came to herbals through personal recommendation.

By some way the most widely used of all herbals was turmeric, taken by **ONE IN FIVE** (21%) of respondents. Turmeric was found to be beneficial by 63% of users, with 22% finding it highly effective.

Ginger has been used by 14% of respondents and was also highly rated for effectiveness. 65% of users reported some benefit.

CBD oil has been used by over 12% of our respondents and was ranked third most effective supplement, with 49% reporting some benefit.

Used by 12% of our respondents, cannabis was rated as highly effective by **ONE IN FOUR** (26%) of all users, some of whom were medically prescribed. Those who were not medically prescribed felt conflicted about non-prescribed usage. As one respondent put it: "cannabis helped me live a normal life [but] it's expensive, and it's illegal".

The least effective of herbal medicines was cat's claw, found to be largely ineffective by 78% of users. Rosehip (62%) and frankincense (62%) were also reported as largely ineffective.

Notably, 45% of herbal medicine users relied on personal recommendation, with usage often being prompted by delays in treatment and flare-ups.

Lesser-used herbals include buckthorn oil, feverfew, knotweed tincture, lemon balm, meadowsweet and sea moss.

"I've tried so many herbal lotions and potions over many years of suffering with severe joint pain and can honestly say I've been disappointed time after time."

"I am a legal medical cannabis patient... it has enabled me to stop taking 80 milligrams of morphine a day."

"CBD oil for pain relief has been a game changer."

PSYCHOLOGICAL THERAPIES

ONE IN FOUR

(26%) survey respondents have used at least one form of psychological therapy, exactly half doing so after a recommendation from a healthcare professional.

MINDFULNESS AND MEDITATION RANKED HIGHEST IN TERMS OF USAGE,

having been tried by **38%** of respondents. Both were found effective in some degree by approximately two out of three users **(66%).** Numbers reporting high levels of effectiveness were significant **(28%).**

CBT HAS BEEN USED BY ONE IN SIX

(16%) respondents but was markedly less effective than mindfulness and meditation. Only **44%** found CBT in any degree beneficial.

Other psychological therapies used for self-management include:

AUTOGENIC TRAINING, EMOTIONALLY FOCUSSED THERAPY (EFT) AND BREATH WORK.

"Mindfulness and meditation help to relax me."

"Emotional freedom techniques are good for managing pain."

"I cannot see how psychological therapies can help with physical pain."

"I'm not comfortable talking to people, especially about my weaknesses/pain."

ENGAGEMENT WITH HEALTHCARE PROFESSIONALS

39%

of respondents reported accessing a complementary or alternative treatment via the NHS, but the majority of these referrals were for physiotherapy.

LEAVING THESE REFERRALS ASIDE, LESS THAN ONE IN TEN

of all respondents (9%) were referred for alternative therapies or self-management through primary care. Most of these referrals were for acupuncture (38%), hydrotherapy (32%), pain management classes (31%), and CBT (12%).

ONE IN THREE

(36%) of respondents learned about a self-management treatment or therapy that they had used from a healthcare professional.

DISCUSSION OF SUPPLEMENTS AND HERBAL REMEDIES

was very limited (16%), but more engaged on psychological therapies (50%), exercise (49%), and physical therapies (46%).

Respondents'

EXPERIENCE WITH HEALTHCARE PROFESSIONALS

on the subject of self-management was extremely mixed across both primary and secondary care.

"Was told not to waste my money."

"The choice was entirely up to me. Was told to try it and see if it did make a difference. Not a positive response!"

"I can't even get my GP to refer me to a pain clinic. I need alternative treatments that work."

"My consultant surgeon confirmed the research I had read... He did not rule out or cast aspersions on any supplements that I felt helped."

"GPs and NHS healthcare colleagues have to open up and recognise that alternative medical options DO EXIST and could well benefit SOME patients."

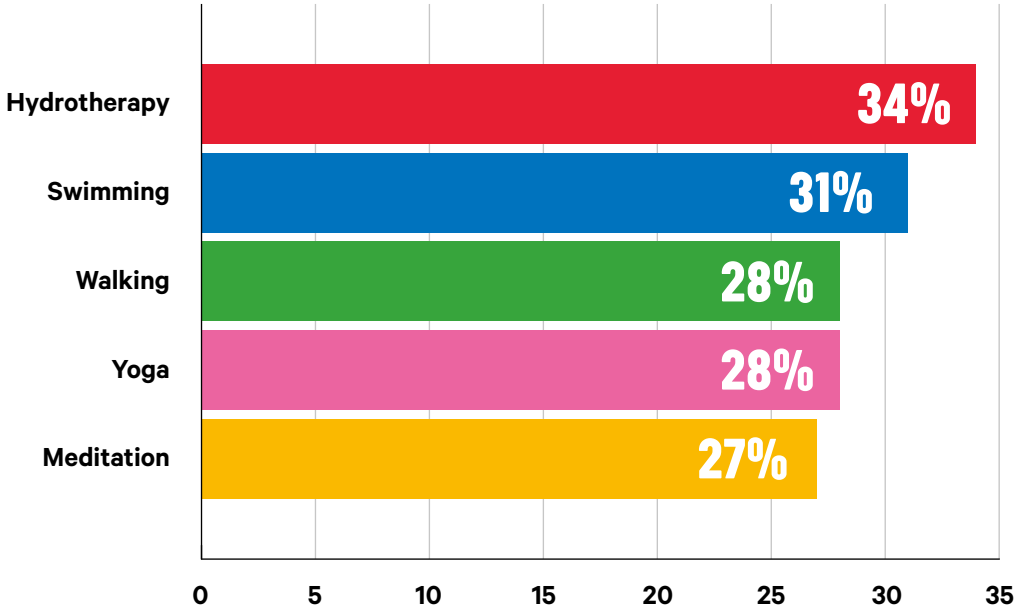
General conclusions

Most Used Forms of Self-Management

71%	57%	45%	42%	40%
Walking	Stretching	Vitamins	Classes	Swimming

The perceived effectiveness of treatments, therapies and interventions that fall under the umbrella of self-management is highly variable, ranging from a 20% positive response for some herbal remedies to over 70% for hydrotherapy, massage and several forms of exercise.

Top Five Treatment and Therapies (ranked 'highly' or 'extremely' effective):



While a significant number of users report life-changing benefits from self-management – some respondents with autoimmune conditions report that CAM helped push them into remission – many feel angry and disappointed that the results of treatments and therapies did not match their expectations:

> **"Alternative medicine and therapies have cost me a lot of money and not delivered results."**

> **"I've wasted a lot of money trying different supplements, nothing helps."**

Self-management was felt by many not to be a choice but a necessity, forced upon them by a lack of healthcare support, delays to treatment, side-effects of conventional medication, and an inability to find relief from pain and other symptoms.

> **"Alternative therapy was not supported or recommended to me by either the surgeon or physio."**

> **"It would be useful if when you are diagnosed with arthritis [you could be given] a list of all things you could try instead of finding out all information by yourself."**

A lack of information was reported to be the greatest barrier to self-management uptake, and uncertainty around interactions with prescribed medications was a common concern among those who had not experimented with herbal remedies and supplements.

One in three of all respondents (34%) had used Versus Arthritis' online information on complementary and alternative treatments, and 93% found our information helpful. Free-text feedback was also extremely positive, though some users pointed to a lack of information around diet and alternative practitioners.



Users of Versus Arthritis' health information placed great stock in the fact that our information is evidence-based and free from commercial interests, and this was particularly welcomed by those seeking information on supplements, herbal medicines and alternative therapies.

Since only a minority of patients with arthritis disclose their use of CAM to healthcare professionals, and because impartial, evidence-led information on the potential risks and benefits of treatments and therapies is not widely available online, Versus Arthritis has an opportunity to maximise its influence, reaching even greater numbers of CAM consumers, patients and healthcare professionals.

For more information please visit
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