



## Healthwatch Plymouth

### Sarcoidosis

October 2017



Healthwatch is the consumer champion for health and social care in England. We give children, young people and adults a powerful voice to influence and challenge how services are provided in the city by making sure their views and experiences are heard by those who run, plan and regulate local health and social care services.

In 2012 the Health and Social Care Act set out that each local authority should establish a local Healthwatch. In 2013, Plymouth City Council undertook a competitive tender process and awarded the contract to an established local organisation called Colebrook (SW) Ltd.

Experienced in public and patient involvement, Colebrook launched Healthwatch Plymouth in April 2013, ensuring independence through its governance structures and a memorandum of understanding between those working in and delivering the services, and the organisation itself.

## Background

In March 2017, Healthwatch Plymouth had contact with a member of the public who wished to leave some feedback about his experiences with his GP Surgery. During the course of receiving this feedback we became aware that the individual had been diagnosed with a condition called Sarcoidosis. The individual then gave us feedback around the issues he had whilst being treated for this condition and the lack of support that was currently available.

## Sarcoidosis

Sarcoidosis is classed as a rare condition. According to the Sarcoidosis UK<sup>1</sup> website, it is 'where lumps called granulomas develop at different sites within the body. These granuloma are made up of clusters of cells involved in inflammation. If many granuloma form in an organ, it can prevent that organ from working properly'.

The website goes on to state that 'Sarcoidosis can affect many different parts of the body. It often affects the lungs but can also affect the skin, eyes, joints, nervous system, heart and other parts of the body. The condition can occur at any age, but commonly affects adults in their 30s or 40s.'

Information on the website also says 'The exact cause of sarcoidosis is not known and so far no single cause triggering sarcoidosis has been identified. Sometimes, the symptoms can start suddenly and don't last long. In other patients, the symptoms may develop gradually and last for many years. The symptoms of sarcoidosis depend on which part of the body is affected and patients may feel

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<sup>1</sup> <http://sarcoidosisuk.org/>

tired and lethargic, lose weight or suffer with fevers and night sweats. Some people don't have any symptoms at all.'

It is difficult to quantify the number of people who have been diagnosed with Sarcoidosis from available data. We asked the NHS England (South West) Patient Experience Manager if he could provide numbers of Sarcoidosis patients in the South West and he was unable to determine this from NHS Data. The only information we could find on the number of people diagnosed with the condition is from two websites:

- From the British Lung Foundation<sup>2</sup> website, as of 2012 there were approximately 108,000 diagnosed patients in the UK, whilst a further 4500 being diagnosed that year
- The Sarcoidosis UK website goes further by saying that 'Most specialists agree that around 1 in every 10,000 people have sarcoidosis in the UK. Every year in the UK around 3,000 people are diagnosed with sarcoidosis.'

Diagnosis - The Sarcoidosis UK website states 'Sarcoidosis is difficult to diagnose because the symptoms resemble other diseases. There is no single test to diagnose sarcoidosis.'

Because Sarcoidosis mimics other diseases, blood tests sometimes won't reveal helpful inflammatory markers, often causing the patient to feel dejected and unsupported. Some are told their illness is psychosomatic, with no proof. The eventual diagnosis is often one of elimination. In other words, testing for the diseases with similar symptoms and eliminating all diseases which can be tested for. Once these are eliminated doctors may suspect sarcoidosis. This is '*suspected*' or '*probable*' Sarcoidosis.

Sarcoidosis is characterized by *non-caseating* granulomas. The only positive test is tissue biopsy, which can be difficult to access (i.e. in the brain).

Treatment - As Sarcoidosis has no known cause, there is no cure. The condition might resolve naturally without need for medication in around 60% of patients. However, treatment is often necessary for others who experience symptoms or where their condition is affecting the functioning of body organs. Doctors have to use treatment which has proved to be useful in similar conditions. This is usually corticosteroids but for unresponsive patients or those who can't tolerate the side effects, other immuno-suppressants are used.

Information - During our research about Sarcoidosis, we have used information from the following organisations/websites

- Sarcoidosis UK - national charity
- British Lung Foundation - national charity for lung disease
- NHS Choices - NHS Patient Information

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<sup>2</sup> <https://statistics.blf.org.uk/sarcoidosis>

- Royal Brompton & Harefield NHS Foundation Trust - Patient Information

Whilst these websites provide lots of information, what has been clear from patients is that when being diagnosed as having Sarcoidosis they are given no advice on where to find out information about the condition or what support groups are available to them.

Additionally the BMJ Best Practice website also provides information for health professionals.

We also contacted the National Institute for Health and Care Excellence (NICE) to ask whether there was any guidance for healthcare professionals about this condition. We received a response that said there was no clinical guidance on Sarcoidosis, but there were two evidence summaries for the use of infliximab for the treatment of refractory extrapulmonary sarcoidosis and pulmonary sarcoidosis. NICE also stated that guidance on Sarcoidosis was not on their current work schedule as it was not a referred topic by the Department of Health.

Services in the South West - Sarcoidosis services are provided by the specialist commissioning team at NHS England. However from available open source information, it is unclear what services are commissioned and also where they are located. Discussions with the group indicates that they have been referred to clinics at Derriford Hospital in Plymouth and additionally in Bristol.

We have also been made aware that one of the leading specialists for Sarcoidosis in the UK works at the Royal Brompton Hospital in London and will see patients who are referred in to him from other areas of the UK. However, there is a significant cost to an individual from the South West attending an appointment in London in terms of travel and potentially an overnight stay depending on appointment time.

We have requested clarification around Sarcoidosis commissioned services in the South West and the location for those services from NHS England. Specialised Commissioning at NHS England (South) have responded and informed us that '*they commission services related to Interstitial Lung Disease (ILD) at Bristol (North Bristol NHS Trust) and a second in Exeter (Royal Devon & Exeter NHS Foundation Trust).*' These are '*networked with district general hospitals to provide specialist multi-disciplinary clinical supervision of all cases requiring specialist input to enable all patients with significant disease to benefit from the expertise in specialist centres without necessarily having to travel.*' However, '*the network arrangements have yet to be formalised though.*'

They go on to say that '*there is already agreement that Exeter will be the specialist ILD centre in the peninsula and that the MDT at the Royal Devon & Exeter NHS Foundation Trust will discuss cases of ILD from any provider in Devon and Cornwall and make a recommendation about optimal treatment.*'

## Sarcoidosis Support Group - Southwest Sarkies

After receiving the initial feedback around the condition and the lack of any local support group, Healthwatch Plymouth staff suggested to the individual that he may want to consider starting a user led support group utilising Social Media for people with the condition in the South West.

Subsequently a South West support group was formed and held its first meeting in Plymouth on 17 May 2017 where 7 individuals attended along with Healthwatch Plymouth Staff. Subsequent meetings have been held in Exeter and Roche in Cornwall and the user led support group now has 53 members across Devon and Cornwall. Links have also been established with a support group in Scotland and the group is registered with Sarcoidosis UK; the national charity for Sarcoidosis.

From the experiences shared at the first meeting, Healthwatch Plymouth recognised that this group needed to be able to have a voice to be able to share with commissioners and other agencies how they felt they were being served by the services they access for their condition. As such we have worked with 17 members of the support group in capturing the issues they face living with the condition on a day to day basis. Of those we have talked to, some have only recently been diagnosed with the condition whilst others have lived with it for over 20 years. One comment made by an individual who has had the condition for 27 years was *'that issues around diagnosis, treatment and patient experience has not changed during this time'*.

## Living with Sarcoidosis and accessing services

It is clear from talking with patients that this condition leads to many challenges in their day to day lives that affects their general health & wellbeing.

During the July meeting, the group held a workshop and captured comments under 4 headings, Fears, How do you feel, Who's been involved and What Medication are you taking. The comments made under these 4 themes are at Appendix 1. We have also captured individual comments, which are at Appendix 2.

The challenges they face are best summarised as follows:

- Sarcoidosis is a major life changing condition. *'I have become very mindful to live for today as I don't know how I will feel tomorrow, next week, next month'*
- Feeling physically exhausted after making effort to attend events/appointments. *'I need a rest day before events'*
- We are told physical activity helps to manage the condition, but that is difficult when you are constantly short of breath *'No longer able to go on walks or undertake physical activity'* (patients lungs are affected by the condition)
- *'I feel I'm a different me'* - a comment made by everyone we spoke with

- Changes to physical appearance due to steroid treatments. *'I have put on 5 stone. Because of the changes to my physical self, I am self-conscious of my physical shape and I now hide away and feel isolated'*
- Self-esteem takes a knock - public perception is that nothing is wrong with you.
- Medication - Some have to take a variety of tablets to manage the condition, but they have concerns about long term effects of taking a multitude of medication
- Accessing services - lack of information provided or what help may be available with travel costs as some services that patients are referred into need the individual to travel some distance to attend *'I need an injection for my neck condition and the expectation is I will have to go to Salisbury as this is the nearest place that can undertake this. But travel costs worry me as I do not work and my only income is from benefits'*
- There is a lack of understanding of sarcoidosis amongst health professionals *'I have no consistency in seeing the same health professional and constantly have to explain my condition to them'*  
*'I do not feel I am treated holistically for my condition (unlike those diagnosed with Diabetes for example). I feel that I am just given medication to manage the symptom that I present with rather than the condition I have'*  
*'I do not feel supported to self-manage my condition or symptoms'*
- There is so much variation in the way we are treated. Doctors need to admit that sometimes patients know best. If we were taken notice of it would save so much money and time not to mention our conditions and circumstances. *'Many doctors have a god complex and can't admit they are out of their depth. I respect doctors who can respect their limitations. My Doctor was able to do that and I respect him even more'*
- Why is Sarcoidosis not recognised as having serious disabling properties (for PIP purposes) as it can clearly affect an individual's mobility. It is called the snowflake disease as no two people are affected in the same way, the main symptom in people who are disabled is extreme fatigue, whether it affects their lungs or not.
- Reduced employment opportunities because of the nature of an individual's condition. *'I want to be employed, but feel disadvantage at a job interview because of my condition. I do believe that this is a factor of not being able to gain employment, because Sarcoidosis is not recognised as a disability'*

Communication - Although not exclusive to Sarcoidosis patients, communications between services and patients can be hit or miss.

*'I should have been attending a Rheumatology hospital appointment this morning, BUT it was cancelled and the Transport too, BUT no one thought to let me know about the cancellation. I found out by phoning as soon as the telephone line was*

*available at 8.30am. So after a sleepless night, up at 5am to be ready for 7.30am for Transport, I am feeling very fed up and let down.'*

Incidents like this frustrate patients, especially if you have a condition that means you have to physically and/or mentally prepare yourself to attend.

### Healthwatch Plymouth Observations

Diagnosis - It became clear during the meetings that the pathway to a final diagnosis of Sarcoidosis has been varied for each individual with some presenting to their GP with an eye condition, others with a respiratory condition and others with dermatological issues. Due to the variety of the presenting conditions, actual diagnosis of Sarcoidosis has taken time as it appears that any tests that have been conducted are standard ones based on the presenting condition. Sarcoidosis testing seems to only take place when results have proved negative for the perceived condition that an individual is thought to have by the health professional. This leaves individuals worrying about what is wrong with them for a protracted period.

Would it not be more efficient (and cost effective) that when tests are arranged for an ailment where potentially the underlying condition is Sarcoidosis, that this is tested for at the same time, especially if bloods are being taken? This could speed up the diagnosis for the patient and relieve some of the stress and worry that they experience when diagnosis process is protracted.

One individual we spoke with was diagnosed with Lymphoma and had arrived at hospital to start a course of chemotherapy when she was intercepted by the consultant and informed that she didn't have Lymphoma, but had Sarcoidosis instead. The Lymphoma diagnosis was given just before Christmas and whilst this new diagnosis was in some ways a relief, they obviously had had the worry and uncertainty around the original diagnosis over the holiday period.

Knowledge of Condition - From discussions with individuals from the group, it is often commented that there is a lack of understanding of sarcoidosis amongst health professionals in both Primary and Secondary care. Individuals regularly have to explain the condition to the health professional. Subsequently they feel they are only being treated for the symptom that they present with and to the patient their overall condition appears not to be considered when treatment/medication is prescribed.

As an example, one individual wanted to move GP Surgeries and asked the new surgery about looking after him and this condition. The receptionist went to enquire and returned saying they (the Surgery) didn't know about the condition and wouldn't take him on.

In Secondary care, individuals state that they see various consultants for different aspects of their condition, but from their perspective consultants are not talking to

each other and they feel their condition and symptoms are not being treated holistically. Equally they also say they don't always see the same consultant twice for the same symptom for their condition.

All of this becomes very frustrating for the patient as they feel they are no further forward in treating or managing their condition and they often feel unsupported in managing the symptoms. The impression they have is that they are wasting NHS Funds/Resources and as a consequence they feel that their mental health is also suffering in addition to the physical issues they find themselves dealing with.

Services - Sarcoidosis services fall under NHS England's specialist commissioning team. Whilst specialist services have been commissioned in both Exeter and Bristol, it is unclear to patients how these services work and from their perspective they are not joined up. Publically available information about these services is also not clear and the only NHS Trust website that details Sarcoidosis services is the Royal Brompton and Free.

It is also unclear as to whether any 'flagging' system is used on medical records (especially in Secondary Care) to indicate that a patient has sarcoidosis to aid health professionals when treating individuals. For example, if a patient is under a specialist for a lung condition attributed to sarcoidosis and is then referred in to the hospital with a dermatological condition that is also sarcoidosis related, patients feel that they are not being treated holistically for their condition, but merely treated for the symptoms they present with as nothing seems coordinated.

NHS Choices<sup>3</sup> website states 'If you have sarcoidosis, your clinical team will pass information about you on to the National Congenital Anomaly and Rare Diseases Registration Service (NCARDRS).' However, does this actually happen and is it accessible by other areas of the NHS so that they can see potential population size when commissioning services?

Support - Support for individuals with sarcoidosis living in the South West is limited. Until recently there was no patient support group and individuals were left 'stumbling in the dark' trying to get information and advice about the condition. Although there is a National Charity for Sarcoidosis, their main focus has been around research of the condition both nationally and at a European Level. Their website does provide information for both patients and health professionals, but knowledge of the charity and its website appears limited.

For patients, having a named individual that they are able to ask questions of is a must, given the uncertainty they feel generally around the day to day management of their condition. Arguably this individual should be their GP, but given the lack of knowledge and guidance to primary care health professionals about the condition this is very much a lottery. Most individuals we spoke with told us their GP had no

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<sup>3</sup> <https://www.nhs.uk/conditions/sarcoidosis/>



or limited knowledge of the condition and when needing an appointment they often saw a different GP leading to a lack of continuity and support in helping them manage their condition. However, one individual explained that his GP was now fully engaged with him and he found he was now very positive about self-managing his condition; sadly this is not the same for everyone else in the group.

We believe a positive step in providing support would be to have a specialist nurse at each commissioned specialist Sarcoidosis service who is available as the first point of contact for patients when they have queries about their condition.

Day to Day Living - Being diagnosed with Sarcoidosis is a major life change event and affects individuals in different ways. Some are able to manage their symptoms relatively easily and are able to continue to work (within limitations). However, others struggle at times with day to day living because of their symptoms, particularly if their lungs are affected. This leads to shortness of breath and mobility issues as well as also affecting their mental health & wellbeing. Those that are greatly affected by the condition often have to give up employment because they are unable to cope with the day to day routine.

Currently Sarcoidosis is not recognised by the Department of Work and Pensions as a chronic illness with life limiting affects. Subsequently individuals are being turned down for Personal Independence Payments (PIP), including the mobility element, as they do not score enough points during the assessment. It is accepted that all Sarcoidosis sufferers have different limitations, but for those that are greatly affected by the condition, particularly with mobility issues, PIP payments may be appropriate.

## Recommendations

Healthwatch Plymouth has the following recommendations:

- NHS England to consider the ‘flagging’ of medical records of Sarcoidosis patients to
  - a. Enable capture of the total number of patients
  - b. To confirm the annual rate of diagnosis
  - c. Allow Specialist Commissioning to provide services that meets the need of the region they are commissioned in
  - d. Allow health professionals to provide a more holistic approach to care and support for patients
- NHS England (or NICE) to review sources of information and guidance for health professionals around the Sarcoidosis condition and to communicate that to Primary Care services in the South West (and the rest of England)
- NHS England Specialist Commissioning to review that commissioned services meets the current and future needs. Information about services to be (re)

communicated to NHS Trusts and Primary Care in the South West and to be made available to patients via NHS Trust websites

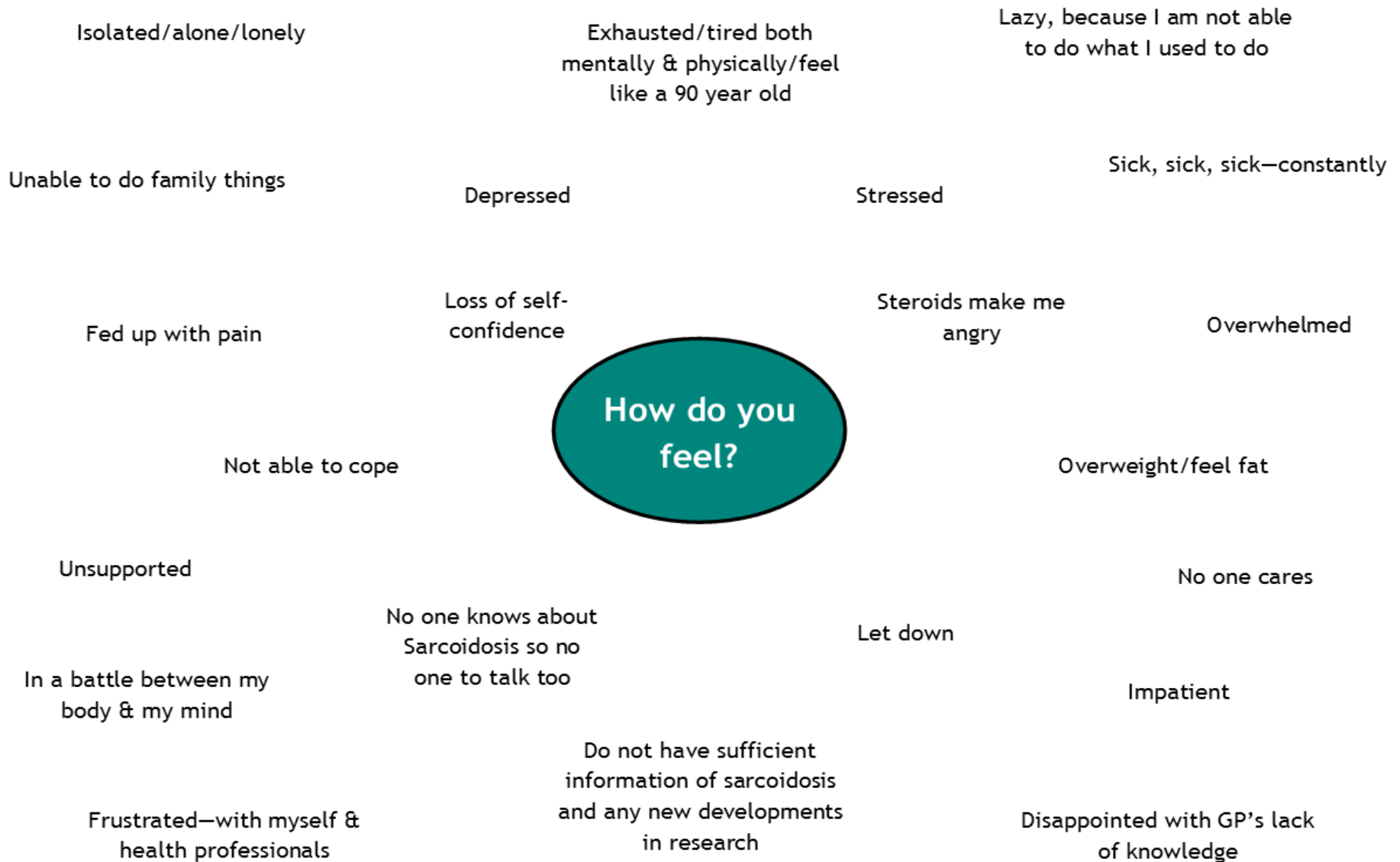
- NHS England Specialist Commissioning to consider introducing Tele Medicine conferencing if an individual is referred to a specialist unit outside of the South West, thus reducing the impact of travel on the individual and the NHS as well as Clinical Commissioning Groups
- NHS England Specialist Commissioning to investigate the use of a specialist nurse as part of a commissioned specialist Sarcoidosis service to provide patient support and information
- Department of Health to consider adding Sarcoidosis to referred topic work plan for NICE to allow guidance to be produced for health professionals
- Department of Health to investigate status of Sarcoidosis and review advice provided to decision makers with a view to adding it to the Chronic Illness list for the Personal Independence Payment benefit coordinated by the Department of Work and Pensions
- If tasked by the Department of Health, NICE to investigate and include streamlined diagnostic testing for sarcoidosis as part of any guidance produced

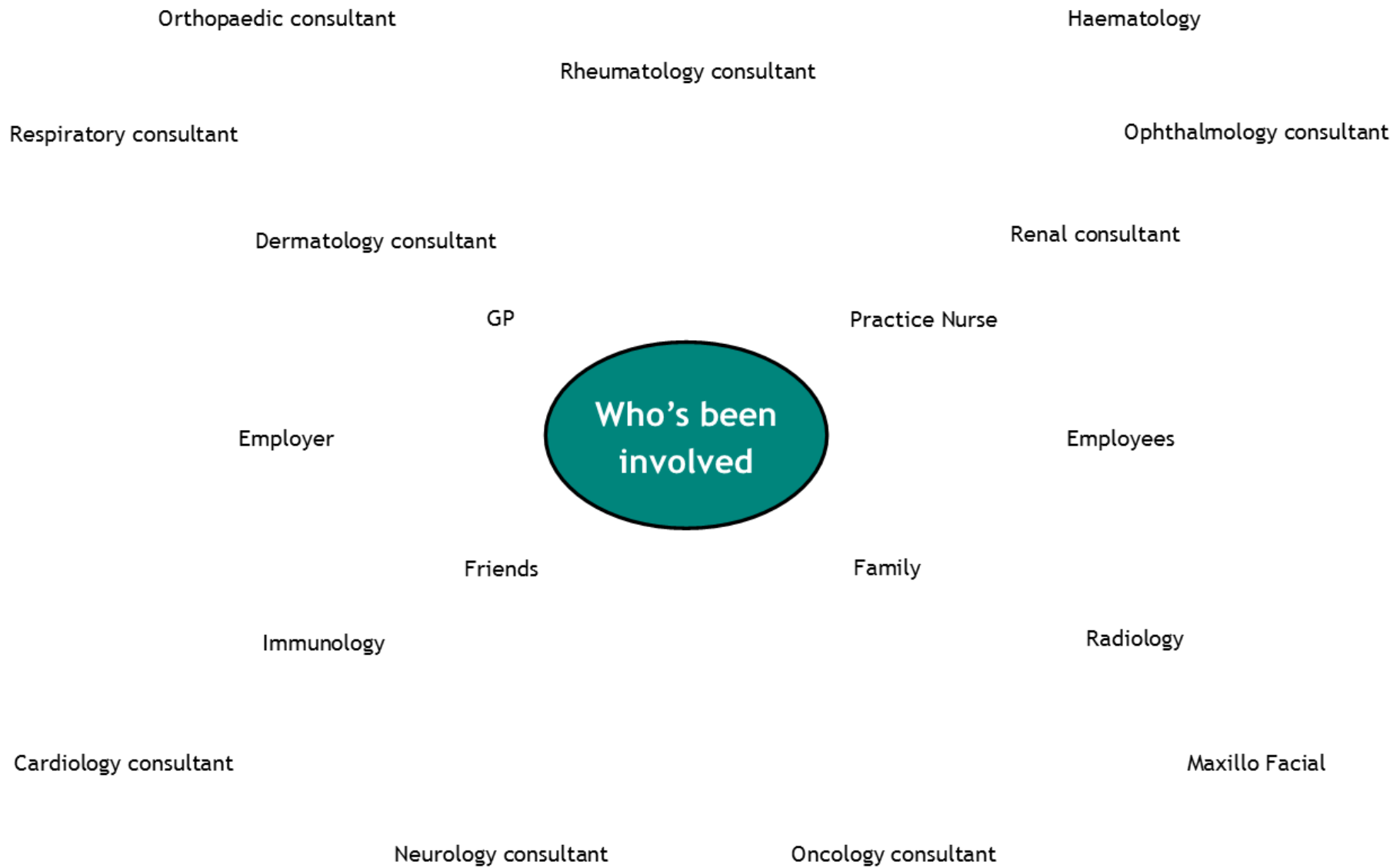
Appendix 1: South West Sarkies Support Group Workshop

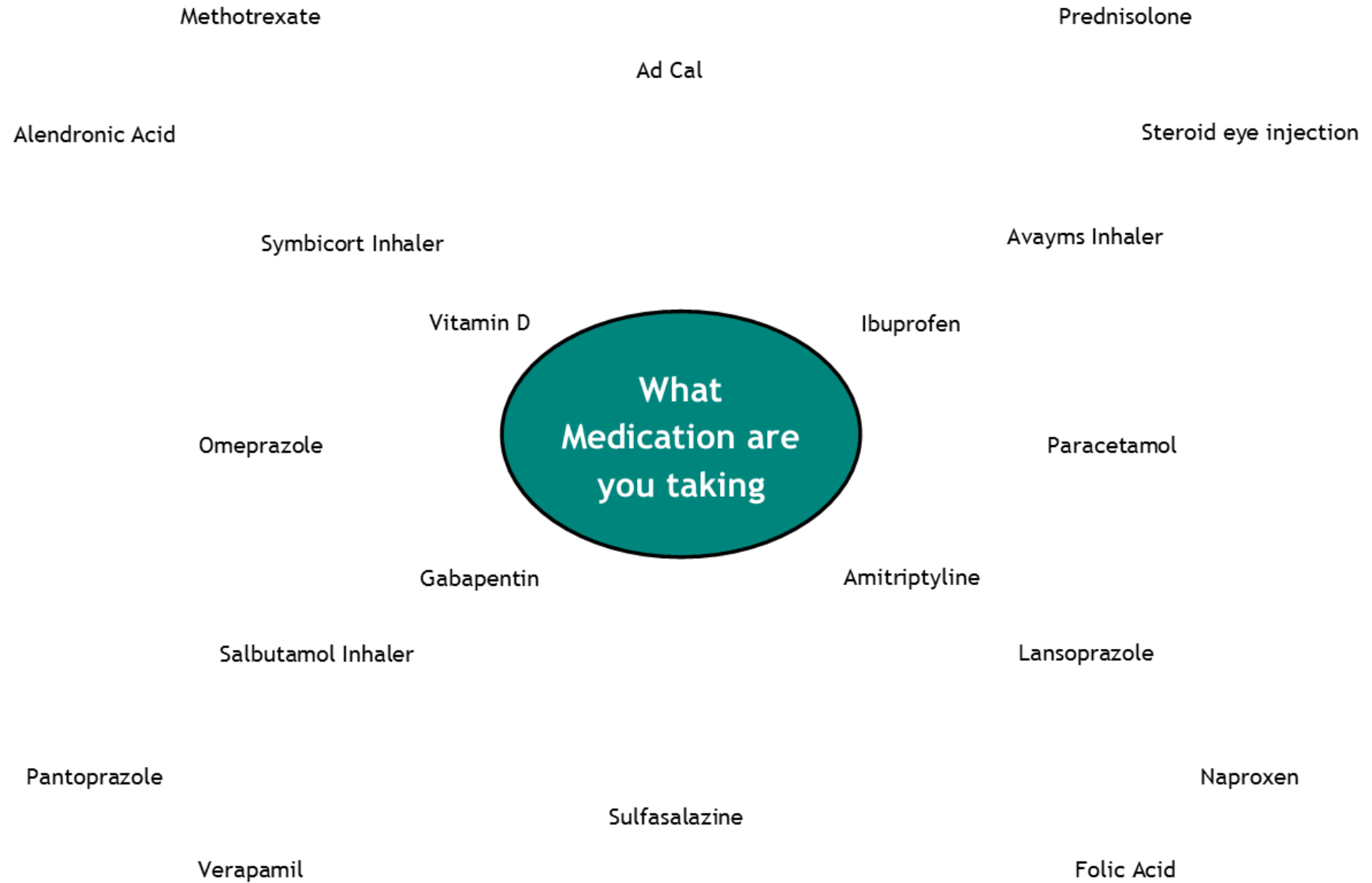
Appendix 2: South West Sarkies - Individual Comments

**SOUTH WEST SARKIES SUPPORT GROUP WORKSHOP**









## SOUTH WEST SARKIES - INDIVIDUAL COMMENTS

Below is a collation of comments over 4 meetings of the support group where Healthwatch has been in attendance.

‘GP doesn’t understand what we’re saying.’

‘My GP won’t refer my daughter for a chest x-ray, says I should ask the chest clinic myself.’ - comment made in relation to heredity concerns for children.

‘Doctor’s don’t know about condition, I end up having to explain it.’

‘Lack of understanding of sarcoidosis amongst health professionals.’

‘No one treating us holistically apart from London.’

‘There is a lack of continuity so you have to explain over and over and you get a different treatment plan. I don’t want to keep seeing different people because they have different ideas.’

‘Go for blood tests, don’t get any feedback about the results.’

‘Outpatient appointment - Say see you in 3 months. Now been waiting since January (5 months).’

‘Illness seems to be a postcode lottery.’

‘Advised to keep fitness levels up, but it is hard. Walking to top of stairs is bad enough.’

‘No one is understanding condition has a huge impact on mental health, let alone the physical conditions themselves.’

‘(The condition) impacts our mental health - flares up and then goes and then comes back.’

‘Nothing has changed in 25 years.’

‘Often told it is in your head.’

‘Was advised by consultant to google my condition (SE England before I moved to the South West).’

‘Being made to feel that I am wasting NHS Funds.’

‘Not getting tests done. There are loads I haven’t had and I just get tablets.’

‘I feel I’m a different me.’

‘Physical appearance has changed (steroids) and I have put on 5 stone.’

‘Medication - I have 1 tablets in the morning and a further 7 at night.’

‘Because of the changes to my physical self I now hid away.’

‘I have become mindful to live for today.’

‘I need an injection for my neck condition and the expectation is I will have to go to Salisbury, but travel costs worry me as I do not work and my only income is from benefits.’

‘Sarcoidosis is a major life change.’

‘I feel wiped out after making effort to attend events/appointments. I need a rest day before events.’

‘No longer able to go on walks (Physically demanding).’

‘Self-esteem takes a knock and individuals feel isolated - public perception is that nothing is wrong with you.’

‘Why is Sarcoidosis not recognised as a disability (for PIP purposes) as it clearly affects an individual’s mobility?’

‘Having a medical ID cards and portable healthcare records, we should definitely have these as we are advised differently every time.’

‘Many doctors have a god complex and can’t admit they are out of their depth. I respect doctors who can respect their limitations.’