Summary of results

Section 1

Introduction and methods

Section 1 Introduction and methodology

Background

Hidradenitis Suppurativa is a painful chronic inflammatory skin disease, it is associated with comorbidities, in particular obesity, acne, hyperlipidaemia, depression, insulin resistance, pilonidal sinus, poly cystic ovary syndrome, diabetes, and hypertension[1]. The estimated prevalence in Australia is 0.67%, however, diagnosis rate is low due to people with HS not seeking help, misdiagnosis, and mismanagement of cases (referral to multiple healthcare providers, undergoing unnecessary investigations and procedures) [2]; [3]; [2]. Female, young age, obesity, and being a smoker are risk factors for HS, in addition, being unemployed or having a low income is associated with HS [2]. The disease is progressive in the majority of patients if it remains untreated. Cessation of smoking seems to lead to a reduction in the severity of the disease and some patients go into remission and weight loss may have a similar effect [4]; [5].

Diagnosis

A diagnosis of HS is based on the nature and type of lesions, and includes an assessment of comorbidities[1]. The severity of disease is classed by the Hurley stage, defined as follows:

Stage 1: Abscess formation: single or multiple, no sinus tracts of scarring
Stage 2: Recurrent single or multiple abscesses with sinus tracts and scaring. Single or multiple, widely separated lesions
Stage 3: Diffuse or almost diffuse involvement or multiple interconnected tracts and abscesses.
[1]

Treatment

Treatment of HS included identification and management of comorbidities, and should also include quitting smoking, weight control, wound care, pain management, itch management and psychosocial health[6:Deckers, 2015 #823]. Stage 1 disease may be managed with topical antiseptic washes or topical antibiotic solutions[6:Deckers, 2015 #823]. Systemic antibiotics is recommended when topical treatments fail, second line therapies may include corticosteroids, and biologic agents[6:Deckers, 2015 #823]. Corticosteroids are effective for debilitating pain and acute flares[6:Deckers, 2015 #823]. Adalimumab is the only biologic registered in Australia for the treatment of HS. Surgery, laser therapy, photodynamic therapy, and intense pulsed light treatment may be used as a supplement to medical therapy. [6:Deckers, 2015 #823]

Personal Experience, Expectations and Knowledge (PEEK)

Patient Experience, Expectations and Knowledge (PEEK) is a research program developed by the Centre for Community-Driven Research (CCDR). The aim of PEEK is to conduct patient experience studies across several disease areas using a protocol that will allow for comparisons over time (both quantitative and qualitative components). PEEK studies give us a clear picture and historical record of what it is like to be a patient at a given point in time, and by asking patients about their expectations, PEEK studies give us a way forward to support patients and their families with treatments, information and care.

Section 2

Demographics

Section 2 Demographics

Demographics

There were 20 people that took part in this study, 19 were diagnosed with Hidradenitis suppurativa, and one was a carer to someone diagnosed with Hidradenitis suppurativa. Participants were aged from 25 to 65 years of age, most were aged 44 years or younger (n=13, 65.00%), 18 participants were females (90.00%)

Participants were most commonly from New South Wales (n=6, 30.00%), and Queensland (n=5, 25.00%). Most participants were from major cities (n=14, 70.00%), and they lived in all levels of advantage, defined by Socio-economic Indexes for Areas (SEIFA) (www.abs.gov.au) with 2 participants (10.00%) from an area with a high SEIFA score of 7 to 10 (more advantage), and 18 participants (90.00%) from an area of mid to low SEIFA scores of 1 to 6 (less advantaged).

There were 7 participants (35.00%) that had completed university to at least an associate degree. There were 10 participants who were employed either full time (50.00%), or part time (n=3, 15.00%). Less than half of the participants were carers to family members or spouses (n=8, 40.00%), most commonly carers to children (n=7, 35.00%).

Baseline health

The Short Form Health Survey 36 (SF36) measures baseline health, or the general health of an individual. The SF36 comprises nine scales: physical functioning, role functioning/physical, role functioning/emotional, energy and fatigue, emotional well-being, social function, pain, general health, and health change from one year ago. The scale ranges from 0 to 100, a higher score denotes better health or function.

SF36 **Physical functioning** scale measures health limitations in physical activities such as walking, bending, climbing stairs, exercise, and housework. On average, physical activities were moderately limited for participants in this study.

SF36 **Role functioning/physical** scale measures how physical health interferes with work or other activities. On average, physical health often interfered with work or other activities for participants in this study.

SF36 **Role functioning/emotional** scale measures how emotional problems interfere with work or other activities. On average, emotional problems seldom interfered with work or other activities for participants in this study.

SF36 **Energy/fatigue** scale measures the proportion of energy or fatigue experienced. On average, participants were almost always fatigued.

The **SF36 Emotional well-being** scale measures how a person feels, for example happy, calm, depressed or anxious. On average, participants had fair emotional well-being.

The SF36 **Social functioning** scale measures limitations on social activities due to physical or emotional problems. On average, social activities were limited for participants in this study.

The **SF36 Pain** scale measures how much pain, and how pain interferes with work and other activities. On average, participants had quite a bit of pain.

The **SF36 General health** scale measures perception of health. On average, participants reported poor health.

The **SF36 Health change** scale measures health compared to a year ago. On average, participants reported that their health is about the same as a year ago.

Section 3

Symptoms and diagnosis

Section 3: Symptoms and diagnosis

Symptoms leading to diagnosis

In the structured interview, participants were asked to describe the symptoms that actually *led* to their diagnosis.

Most commonly participants strongly recalled their symptoms or how they came to be diagnosed (80.00%), Others had an unclear recollection of their symptoms or how they came to be diagnosed (10.00%), or did not respond to the question (10.00%).

The most common symptoms leading to diagnosis were having lumps, boils or cysts (65.00%), abscesses or slow healing abscesses (40.00%), and acne (25.00 %). Other symptoms included scarring (15.00%), and a swollen groin (5.00%).

Symptoms leading to diagnosis: Seeking medical attention

Participants described when they sought medical attention after noticing symptoms. The most common responses were having symptoms and not seeking medical attention initially (55.00%) and having symptoms and seeking medical attention relatively soon (35.00%).

Symptoms leading to diagnosis: Description of diagnostic pathway

In the structured interview, participants described their diagnostic pathway in the healthcare system. The most common descriptions were a complex diagnosis, needing to see multiple specialists before diagnosis (35.00%), and a linear diagnosis after being referred to a specialist from their general practitioner (20.00%). Other themes included being diagnosed by their general practitioner during a routine check-up that was not related to symptoms (15.00%), being diagnosed in an emergency department (10.00%), and being diagnosed by their general practitioner during a routine check-up that was not related to symptoms (5.00%).

Understanding of disease at diagnosis

Participants were asked in the structured interview how much they knew about their condition at diagnosis. The most common responses were knowing nothing or very little about the condition at diagnosis (65.00%) and knowing about the condition by learning about it before or during the diagnostic process (15.00%). Other themes included knowing a good amount about the condition at diagnosis, for example they understood diagnosis and aspects of treatment (5.00%), and knowing about the condition due to professional background (5.00%).

Understanding of prognosis

Participants were asked in the structured interview to describe what their current understanding of their prognosis was. The most common responses were that they had specific medical interventions they need to manage their condition (40.00%), and related to the stage of their condition (30.00%). Other themes included that it was a lifelong condition (20.00%), that it being currently controlled (20.00%) and that it was a serious condition (15.00%).

Section 4

Decision-making

Section 4 summary

Discussions about treatment

Participants were asked to recall what treatment options they were presented with and how they felt about the options. Participants most commonly were presented with multiple options (65.00%), or one treatment option (15.00%). This was followed by no discussions about treatment (10.00 %), and no particular response (10.00%).

In relation to participant in discussions about treatments, for those presented with multiple treatment options, most commonly they did not give a description about discussions (25.00%), they participated in the decision-making process (25.00%), or they changed clinician as they were not satisfied with discussion, lack of empathy and/or options presented (10.00 %). Other themes included that they were comfortable deferring to doctor and accept recommended approach (5.00%), that they were told what to do without discussion (5.00%), and that they wanted more discussion or options (5.00%).

For those with a single treatment option, most commonly they gave no description about participation (5.00%), had some but very little discussion (5.00%), and were told what to do without discussion (5.00 %). Other themes included despite therapies being available (5.00%),and gave no reason (5.00%).

Some participants were presented with no treatment options, describing no treatments offered despite therapies being available (5.00%), and without giving any description (5.00%).

Considerations when making decisions

Participants were asked in the structured interview what they considered when making decisions about treatment. The most common responses were side effects (50.00%), efficacy (45.00%), and cost (40.00 %). Other considerations included quality of life (25.00%), ability to work (20.00%), ability to follow treatments (15.00%), ability to remain independent (10.00%), their own research (10.00%), and impact on their family or dependents (10.00%).

Decision-making over time

Participants were asked if the way they made decisions had changed over time. The most common responses were that they had not changed the way they make decisions (50.00%), that they changed the way they make decisions (40.00%), and others had no particular comment (10.00 %).

Where participants had changed the way they make decisions, the most common reasons were that they were more informed or more assertive (20.00%), they were more aware of their health, responsibilities and limitations (15.00%), and they were more focused on quality of life (10.00 %). Other themes included being more cautious and considered (5.00%) and being more focused impact on family and dependents (5.00%).

Where participants had changed the way they make decisions, the most common reasons were that they were always been informed or assertive (10.00%), that they had no treatment options available or needed yet (5.00%), that they have not had treatment options to choose from (5.00 %), and that they had always considered cost (5.00%).

Personal goals of treatment or care

Participants were asked what their own personal goals of treatment or care were. The most common responses were to maintain their condition or prevent worsening of their condition (30.00%), to have quality of life or return to normality (30.00%) and minimise or avoid side effects (25.00 %). Other themes included to have physical improvements in their condition (20.00%), to get a diagnosis, treatment plan or have better care coordination (10.00%), to not be on medication all the time or to avoid hospitalisation (10.00%), have improvements in mental or emotional health (5.00%), to get through or finish treatment (5.00%), and to make healthy lifestyle changes (5.00%).

Section 5

Treatment

Section 5: Experience of treatment

Description of mild side effects

In the structured interview, participants were asked how they would describe the term 'mild side effects'. The most common descriptions of mild side effects were described using a specific examples (55.00%), and side effects that do not interfere with life (35.00%). This was followed by side effects that can be managed with self-medication or self-management (25.00 %), and side effects that resolve quickly (5.00%).

When a specific side effect was described, the most common responses were rash, dry skin or itchy skin (30.00%), aches and pains (20.00%), and nausea, vomiting or loss of appetite (15.00 %). Other side effects included headaches (10.00%), indigestion (5.00%), lightheaded or dizzy (5.00%), bleeding (5.00%), bloating (5.00%), dry lips (5.00%), and thrush (5.00%).

Description of severe side effects

In the structured interview, participants were asked how they would describe the term 'severe side effects'. The most common description of severe side effects were those that impact everyday life or ability to conduct activities of daily living (40.00%), and described using a specific example (30.00%). Other descriptions of side effects included those that are life threatening or result in hospitalisation (15.00%), side effects that impact their everyday life by being bed ridden (15.00%), side effects that are worse than condition (10.00%), side effects that cause long-term damage to their body (5.00%), side effects that require medical intervention (5.00%), and side effects that cause them to stop taking the treatment (5%).

When a specific side effect was described, the most common examples were allergic reaction (10.00%), and skin blistering or skin eruptions (10.00%). Other side effects included arthritis (5.00%), blood clots (5.00%), fever (5.00%), loss of vision (5.00%), painful urination (5.00%), and tremors (5.00%).

Adherence to treatment

Participants were asked in the structured interview what influences their decision to continue with a treatment regime.

The most common responses were adhering to treatment for a specific amount of time (55.00%), adhering to treatment according to the advice of their specialist or as long as prescribed (50.00%), and adhering to treatment as long as side effects are tolerable (30.00 %). Other themes included adhering to treatment as long as treatment is working (20.00%), needing to see test results/no evidence or reduction of disease (5.00%), and never giving up on any treatment (5.00%).

When participants stated a specific amount of time to adhere to a treatment, the most common amount of time was two to three months (20.00%), and six to twelve months (15.00%). This was followed by one month (10.00 %), and two to three weeks (5.00%).

What needs to change to feel like treatment is working

Participants were asked to describe what needs to change to feel like treatment is effective. The most common responses were needing to see physical signs and symptoms disappear or reduced side effects (85.00%), and needing to see a specific symptom reduction (35.00%). Other themes included needing to see improvements in general wellbeing or quality of life (10.00%), and needing to see evidence of stable disease or no disease progression (5.00%).

What it would mean if treatment worked

As a follow up question, participants were asked what it would mean to them if the treatment worked in the way they described. The most common responses were that it would allow them to do everyday activities/return to normal life (50.00%), and allow them to engage more with social activities and family life (25.00%). Other themes included allow them to return to work (20.00%), less worried about appearance/self image (20.00%), have a positive impact on their mental health (15.00%), lead to a reduction in symptoms/side effects (15.00%), allow them to do domestic tasks (10.00%), and allow them to do more exercise (10.00%).

Section 6

Information and communication

Section 6: Information and communication

Access to information

In the structured interview, participants were asked what information they had been able to access since they were diagnosed. The most common responses were the internet (Including health charities) (65.00%), from other patient's experience (Including support groups) (50.00%), and from journals (research articles) (50.00 %). Other themes included from Facebook and\or social media (45.00%), from a specific health charity (20.00%),their treating clinician (15.00%), and from presentations or webinars from doctors and researchers (5.00%).

Information that was helpful

In the structured interview, participants were asked to describe what information they had found to be most helpful. The most common responses were other people's experiences (25.00%), information about triggers and managing exacerbations (20.00%), and medical journals (15.00 %) were helpful. Other themes included hearing what to expect (e.g. from disease, side effects, treatment) (10.00%), no information especially helpful (10.00%), treatment options (5.00%), all or any (5.00%), YouTube or webinars (5.00%), lay summaries (5.00%), and information about emotional and mental health (5.00%).

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Information that was not helpful

In the structured interview, participants were asked if there had been any information that they did not find to be helpful. The most common responses were no information not helpful (20.00%), other people's experiences (15.00%), and GP or specialist (15.00 %). Other themes included confident in deciding themselves (10.00%), sources that are not credible (Not evidence-based) (10.00%), a lack of new information (5.00%), unsolicited information (5.00%), worse case scenarios (5.00%), not type specific or too general (5.00%), and information from pharmaceutical companies (5.00%).

Information preferences

Participants were asked whether they had a preference for information online, talking to someone, in written (booklet) form or through a phone App. The most common responses were online information (40.00%), and talking to someone plus online information (30.00%). Other themes included written information (10.00%), all forms (10.00%), and talking to someone (5.00%).

The main reasons for a preference for online information were accessibility (35.00%), being able to digest information at their own pace (20.00%), The main reasons for a preference for talking to someone was being able to ask questions (20.00 %). The main reasons for written information were being able to revisit the information (10.00%), and having pictures to help with understanding (5.00%).

Timing of information

Participants in the structured interview were asked to reflect on their experience and to describe when they felt they were most receptive to receiving information. The most common times were continuously (40.00%), and at the beginning (diagnosis) (20.00%). Other themes included two months after diagnosis (10.00%), 12 months or more after diagnosis (10.00%), when seeing someone that was an expert in disease (10.00%), three to four months after diagnosis (5.00%), and not much information at time of diagnosis (5.00%).

Healthcare professional communication

Participants were asked to describe the communication that they had had with health professionals throughout their experience. The most common theme was that participants described having an overall negative (50.00%), overall positive, with the exception of one or two occasions (25.00%), and overall positive (10.00 %).

Healthcare professional communication (Rationale for response)

Participants described reasons for positive or negative communication with healthcare professionals. Participants that had positive communication, described the reason for this was because of holistic with two way, supportive and comprehensive conversations (25.00%), good, with no particular reason given(5.00%), and understood the condition (5.00 %).

Participants that had negative communication, described the reason for this was because of limited because their healthcare professional does not understand their condition (35.00%), and dismissive (One way conversation) (15.00%). Other themes included lacking respect and that they felt vulnerable (5.00%), limited support (5.00%),poor, with no particular reason given (5.00%), and limited in relation health professionals not having a lot of time (5.00%).

Partners in health
The **Partners in Health questionnaire (PIH)** measures an individual's knowledge and confidence for managing their own health.

The **Partners in health: knowledge** scale measures the participants knowledge of their health condition, treatments, their participation in decision making and taking action when they get symptoms. On average, participants in this study had good knowledge about their condition and treatments.

The **Partners in health: coping** scale measures the participants ability to manage the effect of their health condition on their emotional well-being, social life and living a healthy life (diet, exercise, moderate alcohol and no smoking). On average, participants in this study had a moderate ability to manage the effects of their health condition.

The **Partners in health: treatment** scale measures the participants ability to take medications and complete treatments as prescribed and communicate with healthcare professionals to get the services that are needed and that are appropriate. On average participants in this study had a good ability to adhere to treatments and communicate with healthcare professionals.

The **Partners in health: recognition and management of symptoms** scale measures how well the participant attends all healthcare appointments, keeps track of signs and symptoms, and physical activities. On average participants in this study had good recognition and management of symptoms.

The **Partners in health: total score** measures the overall knowledge, coping and confidence for managing their own health. On average participants in this study had good overall knowledge, coping and confidence for managing their own health.

Section 7

Care and support

Section 7: Experience of care and support

Care coordination

The **Care coordination: communication** scale measures communication with healthcare professionals, measuring knowledge about all aspects of care including treatment, services available for their condition, emotional aspects, practical considerations, and financial entitlements. The average score indicates that participants had poor communication with healthcare professionals.

The **Care coordination: navigation** scale navigation of the healthcare system including knowing important contacts for management of condition, role of healthcare professional in management of condition, healthcare professional knowledge of patient history, ability to get appointments and financial aspects of treatments. The average score indicates that participants had poor navigation of the healthcare system.

The **Care coordination: total score** scale measures communication, navigation and overall experience of care coordination. The average score indicates that participants had poor communication, navigation and overall experience of care coordination.

The **Care coordination: care coordination global measure** scale measures the participants overall rating of the coordination of their care. The average score indicates that participants scored rated their care coordination as poor.

The **Care coordination: Quality of care global measure** scale measures the participants overall rating of the quality of their care. The average score indicates that participants rated their quality of care as poor.

Experience of care and support

In the structured interview, participants were asked what care and support they had received since their diagnosis. This question aims to investigate what services patients consider to be support and care services. The most common responses were that they did not receive any formal support (50.00%), or that they found support from the hospital or clinical setting (15.00%). Other themes included peer support or other patients (10.00%), and psychologist or counselling service (5.00%).

Section 8

Quality of life

Section 8: Quality of life

Impact on quality of life

In the structured interview, participants were asked whether they felt that their condition had affected their quality of life. Most commonly, the descriptions suggested that there was an overall negative impact on quality of life (75.00%), and overall a minimal impact on quality of life (5.00%).

The most common themes in relation to a negative impact on quality of life were emotional strain (including family/change in relationship dynamics) (35.00%), and reduced capacity for physical activity/needing to slow down (25.00%). Other themes included intimacy challenges (20.00%), reduced social interaction (20.00%), financial strain (10.00%), managing side effects and symptoms (10.00%), and the impact on self image (10.00%).

The most common theme in relation to a positive impact on quality of life was that it brings people together/highlights supportive relationships (10.00%).

Impact on mental health

In the structured interview, participants were asked if there had been an impact on their mental health. Most commonly, the descriptions suggested that overall, there was at least some impact on mental health (80.00%), overall, there was no impact on mental health (5.00%), and other or mixed experience (5.00 %).

Regular activities to maintain mental health

In the structured interview, participants were asked what they needed to do to maintain their emotional and mental health. The most common response was mindfulness and/or meditation (40.00%), no activities to maintain mental health (20.00%), and the importance of family and friends in maintaining their mental health (15.00 %). Other themes included consulting a mental health professional (10.00%), allowing time to cry, then gets on with it (10.00%), keeping busy (10.00%), coping strategies such as remaining social, lifestyle changes and hobbies (5.00%), the importance of physical exercise (5.00%), and keeping informed about their condition (5.00%).

Regular activities to maintain health

In the structured interview, participants were asked what were some of the things they needed to do everyday to maintain their health? The most common activities for general health were complying with treatment/management (45.00%), and hygiene routine (45.00%). Other themes included avoiding flare triggers (25.00%), understanding their limitations (20.00%), being organised and planning ahead (10.00%), using complementary therapies (10.00%), maintaining a healthy diet (10.00%), mindfulness and/or meditation (10.00%), doing physical exercise/physically active (10%), self care e.g. more rest, accepting help, pacing (10.00%), covering up lesions (10.00%), being aware of their body and limitations (5.00%), and maintaining a normal routine (5%).

Experience of vulnerability

In the structured interview, participants were asked if there had been times that they felt vulnerable. The most common responses were that they felt vulnerable experiencing side effects from treatment or symptoms from condition (25.00%), when having sensitive discussion (diagnosis, treatment decision) (20.00%), and because of interactions with the medical team (20.00 %). Other themes included during/after treatments (15.00%), during diagnostic procedure (10.00%),thinking about disease course/incurable condition (10.00%), and did not feel vulnerable (5.00%).

Methods to manage vulnerability

In the structured interview, participants described ways that they managed feelings of vulnerability. The most common ways to manage vulnerability were getting support from family and friends (15.00%), and using self-help methods (resilience, acceptance, staying positive) (10.00%). Other themes included support from mental health professionals (5.00%), being informed and knowing what to expect (5.00%), and sticking to their treatment regimen (5.00%).

Impact on relationships

Most commonly, the descriptions suggested that overall, there was a negative impact on relationships (50.00%), and overall, there no impact on relationships (15.00%). Other themes included overall, there was a positive impact on relationships (10.00%), and overall, there was an impact on relationships that was both positive and negative (5.00%).

The most common themes in relation to having a negative impact on relationships from people not knowing what to say or do and withdrawing from relationships (20.00%), from feeling dismissed or not believed by others(10.00%), and due to intimacy challenges (10.00 %). Other themes included from managing symptoms (5.00%), and from the dynamics of relationships changing due to anxiety, exacerbations and/or physical limitations of condition (5.00%).

The most common theme in relation to a positive impact on relationships were brings people together/highlights supportive relationships (10.00%).

Burden on family

In the structured interview, participants were asked whether they felt that their condition placed additional burden on their family. Most commonly, the descriptions suggested that overall, there was a burden on their family (60.00%), overall, there was not a burden on their family (15.00%), and having no particular comment (25.00 %).

The main reasons that participant described their condition being a burden were the extra financial assistance needed (10.00%), the mental/emotional strain placed on their family (10.00%), and that the burden on family was temporary or only during treatment (10.00 %). Other themes included the extra assistance needed getting to appointments (5.00%), intimacy problems (5.00%),managing symptoms (5.00%), and eding to take time off work (5.00%).

The main reason that participant described their condition not =being a burden were because they were independent and did not need any help (15.00%), and that they were not a burden because no one knows about their diagnosis (5.00%).

Cost considerations

In the structured interview, participants were asked about any significant costs associated with having their condition. The most common descriptions were that overall, there was at least some cost burden (75.00%), and overall, there was no cost burden (15.00%).

Where participants described a cost burden associated with their condition, it was most commonly in relation to the cost of treatments (including repeat scripts) (65.00%), the cost specialist appointments (50.00%), and needing to take time off work (25.00 %). Other themes included needing a special diet or lifestyle adaptation (15.00%), a family member needing to take time off work (10.00%),the cost of parking and travel to attend appointments (including accommodation) (5.00%), and diagnostic tests and scans (5.00%).

Where participants described no cost burden associated with their condition, it was most commonly in relation to them prioritizing going to work over attending appointments (5.00%), being able to afford all costs(5.00%), and they had no treatment or management (5.00 %).

Section 9

Expectations and messages to decision-makers

Section 9: Expectations of future treatment, care and support, information and communication

Expectations of future treatment

Participants were asked in the structured interview what their expectations of future treatments are. The most common responses were that future treatment will be more affordable (70.00%), will include having choice (including availability/accessibility) and transparency/discussions in relation to treatment options (pathways) (50.00%), and have fewer or less intense side effects/more discussion about side effects (30.00 %). Other themes included remain important but we cannot ignore prevention, awareness and education (25.00%), be easier to administer and/or able to administer at home and/or less invasive (20.00%), be curative (10.00%), involve more clinical trials (including to access new technologies and treatments and funding) (10.00%), allow for a normal life/quality of life (5.00%), and be more effective and/or targeted (personalised) (5.00%).

Expectations of future information

Participants were asked in the structured interview if there was anything that they would like to see changed in the way information is presented or topics that they felt needed more information. The most common responses were that future information will help to inform the community and decision-makers about their condition (raise awareness) (35.00%), and be more accessible/easy to find (30.00%). Other themes included be easier to understand (20.00%), provide more details about the causes of their condition (15.00%), include more scientific and validated information (10.00%), include the ability to talk to/access to a health professional (5.00%), provide more details about where to find support (including peer support/support groups) (5.00%), and provide more details about where to find support (including peer support/support groups) (5%).

Expectations of future healthcare professional communication

Participants were asked in the structured interview what they would like to see in relation to the way that healthcare professionals communicate with patients. The most common expectations for future healthcare professional communication were that communication will be more empathetic (50.00%), and include health professionals with a better knowledge of the condition (45.00%). Other themes included include listening to the patient (20.00%), satisfied with experience (15.00%), and be more understandable (5.00%).

Expectations of future care and support

Participants were asked in the structured interview whether there was any additional care and support that they thought would be useful in the future, including support from local charities. The most common expectation for future care and support was that it will include practical support (home care, transport, financial) (30.00%), and will include specialist clinics or services where they can talk to professionals (in person, phone, online) (30.00%). Other themes included will include being able to connect with other patients through peer support (support groups, online forums) (20.00%), include more access to support services (20.00%),will include access to better products such as dressings and underwear (15.00%), will be more holistic (including emotional health) (5.00%), and will include health professionals with a better knowledge of the condition (5.00%).

What participants are grateful for in the health system

Participants were asked in the structured interview what aspects of the health system that participants are grateful for. The most common responses were that participants were grateful for low cost or free medical care through the government (65.00%), healthcare staff (including access to specialists) (40.00%), and the entire health system (25.00 %).

Some participants noted things that needed improvements. The most common responses were that participants were grateful for timely access to diagnostics (10.00%), and the importance of seeing the same doctor and having some control over appointment times (10.00%). Other themes included treatment and medical care close to home (5.00%), the need for quicker access to treatments (5.00%), not being grateful for anything (5.00%), and that regional health needs to be improved (5.00%).

Messages to decision-makers

Participants were asked, "If you were standing in front of the health minister, what would your message be in relation to your condition?" The most common messages to the health minister were to invest in research (including to find new treatments) (50.00%), to be compassionate and empathetic (30.00%), and the need for timely and equitable access to support, care and treatment (30.00%). Other themes included to invest in professional development so that clinicians understand the condition (25.00%), to help raise community awareness (20.00%), that treatments need to be affordable (20.00%), to take the condition seriously (15.00%), that dressings need to be affordable (15.00%), to understand the financial implications (and provide financial support) (10.00%), to have a holistic approach to the condition (including emotional support) (5.00%), to improve wait times (5.00%), to invest in health professionals to service the patient population (5.00%), and to invest in screening/early detection (5.00%).

Section 10

Advice to others in the future: The benefit of hindsight

Section 10: Advice to others in the future

Anything participants wish they had known earlier

In the structured interview, participants were asked if there was anything they wish they had known earlier. The most common things that participants had wished they'd known earlier were to be assertive, an advocate, informed, and ask questions (45.00%), and wished they had gotten a diagnosis sooner (25.00%). Other themes included to pace themselves or know triggers and limitations (20.00%), had no particular comment and were satisfied with experience (10.00%), and to understand the costs of treatment and management (5.00%).

Aspect of care or treatment they would change

In the structured interview, participants were asked if there was any aspect of their care or treatment they would change. The most common themes were that they would have liked to have had access to a specialist in their condition sooner (25.00%), and would have liked health care professionals to have had more knowledge and awareness of their condition (20.00%). Other themes included would have stopped or changed treatment sooner (10.00%), would have liked to have had a better understanding of their condition (10.00%), would not change any aspect of their care or treatment, with no reason given (5.00%), would have liked more time and personalised attention with healthcare professionals (5.00%), would have switched health professionals (5.00%), would like to change a lot or all of their treatment, without giving specific details (5.00%), would have changed a single negative experience (5.00%), and wanting treatment closer to where they live (5.00%).