

LIVING WITH A RARE CONDITION: THE EFFECT ON MENTAL HEALTH



**RARE
DISEASE UK**

ABOUT RARE DISEASE UK



Rare Disease UK is a multi – stakeholder campaign run by Genetic Alliance UK, working with the rare disease community and the UK’s health departments to effectively implement the UK Strategy for Rare Diseases.



Genetic Alliance UK is the national charity working to improve the lives of patients and families affected by all types of genetic conditions. We are an alliance of over 200 patient organisations.



SWAN UK (syndromes without a name) is a patient and family support service run by Genetic Alliance UK. SWAN UK offers support and information to families of children with undiagnosed genetic conditions.

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Disclaimer: Following its first use, the term ‘carer’ is used as shorthand for ‘parent and carer’.

FOREWORD



Good mental health and emotional wellbeing is important to everyone. Over recent years we have seen steadily increasing recognition that meeting a person's mental health needs is every bit as important as treating the physical manifestations of disease. It is now accepted that living with a chronic condition can have negative impacts on a person's mental health. As a consequence there is a growing awareness of the importance of addressing the mental and emotional needs, as well as the physical needs, of patients with long term conditions.

In stark contrast to common conditions, levels of awareness are low amongst professionals of the specific issues faced by people with rare conditions. Diagnosis can take years, there are few curative treatments available, and rare diseases often require care from several – largely uncoordinated – specialities.

The interplay between mental health and living with rare conditions has not been explored in the UK, until now. The first step to addressing an unmet need is recognising that it exists. To do this we must understand the experiences, needs and preferences of those upon whom the impact is greatest. In exploring the experiences of patients and carers, this report highlights the disparity between the mental health needs of rare disease patients and the provision of services to meet those needs.

Delivering the right assessment and interventions, in the right way and at the right time has transformative potential. We believe mental health services for patients with rare diseases should be commissioned as an integral part of rare disease care, and that this could significantly help to bridge the apparent gulf between the level of care that is clearly needed, and that which is provided.

We thank the patients and carers who took part in this study for their willingness to share their views and experiences, and without whom this report would not have been possible. We commend this report, with patient voice at its heart, as essential reading for all those involved in the commissioning and provision of care and support to those affected by rare disease.



Dr Jayne Spink
Chair, Rare Disease UK
Chief Executive, Genetic Alliance UK

INTRODUCTION

This work arose from an inquiry conducted by the All Party Parliamentary Group on Rare, Genetic and Undiagnosed Conditions, where patient, carer, and patient group representatives raised the mental health issues they face and the lack of support they receive to address them. This work has been funded by public donations to the Rare Disease UK campaign, which is run by Genetic Alliance UK.

A rare disease is defined by the European Union as one that affects fewer than 5 in 10,000 of the general population. There are between 6,000 and 8,000 known rare diseases and around five new rare diseases are described in the medical literature each week. In the UK, a single rare disease may affect up to about 30,000 people. The vast majority of rare diseases will affect far fewer than this – some will affect only a handful, or even a single person in the whole of the UK. Often rare diseases are chronic and life-threatening. Most rare diseases (about 75%) affect children.

Diagnosis can take years, and the majority of patients receive at least one misdiagnosis on the way. Around 80% of rare diseases have a genetic component and are complex, affecting several systems of the body. For these diseases, care is correspondingly complex, requiring the input of several specialisms. In the majority of cases, this complex care is not well coordinated. Even with a diagnosis, there are very few effective treatments for rare diseases.

There is a good body of information about the impact of living with chronic or progressive conditions on emotional wellbeing and mental health. In some cases these conditions will also be rare. We have a long understood through anecdotes from members of Rare Disease UK,

Genetic Alliance UK, and SWAN UK that the impact of living with a rare disease is significant and is often linked to some of the challenges that are particular to rare diseases – but until now we have not had a full and clear picture.

Methodology

We explored the experience and reflections of patients, parents and carers through semi-structured interviews and an online survey. In each stage, participants were recruited by advert through the networks of Genetic Alliance UK, Rare Disease UK and SWAN UK. Interviews were carried out with eight patients, and eight carers, selected to represent those with and without a diagnosis, and to represent variation in the underlying pathology (where known), age of onset and complexity and prevalence of the rare disease. Interviewees' ages ranged from 20s to over 70 years, included men and women, and participants were drawn from all four nations of the UK. Themes from the interviews, along with findings from published literature, were used to develop the online survey: 1,350 patients and 571 carers filled in the survey. Key findings of the interviews and survey led to a series of recommendations for improvement which were refined through consultation at a workshop with external stakeholders.

Stakeholders included representatives of patient organisations, health professional organisations, and health services as well as individual clinicians and patients and carers. This work was supported by an advisory group which included patients, carers, clinicians, a representative of a national mental health charity and a social science academic. The study was approved by the Social Care Research Ethics Committee.

RECOMMENDATIONS

- 1. Healthcare professionals should be provided with the skills, knowledge and capacity to:**
 - **Demonstrate awareness of the emotional challenges of living with a rare disease;**
 - **Handle discussions about mental health sensitively.**

Target: Departments of Health, Health Education England, NHS Education for Scotland, Health Education Wales¹, Department of Health Northern Ireland, NHS England, NHS Wales, NHS Scotland, NHS Northern Ireland, colleges of medicine and medical schools.

- 2. Patients and carers should be routinely signposted to sources of support by healthcare professionals.**

Target: Departments of Health, Health Education England, NHS Education for Scotland, Health Education Wales, Department of Health Northern Ireland, NHS England, NHS Wales, NHS Scotland, NHS Northern Ireland, colleges of medicine and medical schools.

Commitment from Genetic Alliance UK: to seek funding to pilot and design a programme to develop training and resources for rare and genetic condition patient support groups to play a role in supporting the mental health needs of their community.

- 3. Coordinated rare disease services should include assessment of mental health needs and access to mental health services. This should be extended to carers.**

Target: NHS England, NHS Wales, NHS Scotland, NHS Northern Ireland, Rare Disease Advisory Group.

¹ Once established in October 2018.

THE LIVED EXPERIENCE OF PATIENTS AND CARERS

Living with a rare condition can have a huge impact on emotional wellbeing and mental health

It is well known that living with a chronic or progressive condition can adversely affect mental health, and that poor mental health can in turn have a detrimental effect on physical symptoms². In addition, for some conditions mental health problems are directly associated with the underlying diagnosis (for example, some neurological conditions).

Rare disease patients and carers participating in this study reported a huge emotional impact from living with their rare disease. Our research has found that the particular challenges of having a rare disease, or caring for someone with a rare disease, can also negatively impact on wellbeing and mental health. Our research participants described the impact of the difficulties they faced in trying to reach a diagnosis, which can be exacerbated by low awareness and not being believed by healthcare professionals when presenting with symptoms. They also reported that the lack of treatment options has an impact, as does poor care coordination. Even where services are relatively well coordinated, mental health care is rarely incorporated. Carers of children with

very complex conditions – which frequently remain undiagnosed for life – also face mental health challenges.

Because of their rare disease, 95% of respondents to our survey have felt worried or anxious, 93% have felt stressed, 90% have felt low, 88% have felt emotionally exhausted and 70% have felt at breaking point.

All the time spent on the paperwork and the organising encroached on [family time] and left us wrecked I would say. And with this whole extra level of stress...the dominos started to tip.
Patient

I've sort of pushed for things myself and had to practically beg for help, and you do get to the point where you just want to lie down and not be bothered by anyone, not eat, not to anything...[but] because you want to have a life, you're fighting it all the time and that's constant stress on your mind, body, on everything, every aspect of your life.
Patients

You're planning what they're going to be doing in [their] first year...playing in the garden... sharing a room, you know. And then when you have a diagnosis, and for us it was massive [he was] really poorly, he can't walk, he can't see, he can't eat, it was really like the worst of everything... so it's as if he's died but he's still with us. It's really, really difficult to accept.
Carer

I've finally got used to the fact that I'm quite an emotional person now. I never used to be. Again

² Kings Fund/ Centre for Mental Health “Long term conditions and mental health. The cost of co-morbidities.” 2012.
Neurological Alliance UK “Parity of esteem for people affected by neurological conditions.” 2017.
The NHS Five Year Forward View. 2014.

that's the depression side of things. And even when I've talked about good things, like if someone praises my daughter... I well up and I'm much more emotional... I can't control it at all.

Patient

A proportion of respondents to our survey also had suicidal thoughts (36% of patients and 19% of carers).

It's like you don't want to die, you just want some help and a little bit of relief, for someone to take onboard what you're saying seriously and not tell you it's all in your head, because I think more than anything, I mean the pain's bad enough and the other [physical] symptoms, but this, it's like mental – I feel like I'm being tortured every single day, that's what it's like.

Patient

About 88% of respondents felt that poor awareness of their rare condition among healthcare professionals had had a negative impact on their mental health, 83% felt that the process of trying to get a diagnosis had had a negative impact, 80% that not being believed by healthcare professionals had had a negative impact, and 79% that poor care coordination had had a negative impact.

My GP keeps telling me that my disease is so rare, he doesn't have time or need to learn about it and starts every consultation with 'what am I googling today then?' which really upsets me as I feel I don't matter.

Patient

I understand that due to the nature of my daughter's rare neurological disease that there is not much information available but the lack of support is shocking...having never been in this situation before, I now find myself in a head spin with nowhere to turn to for help and support.

Carer

[Trying to get a diagnosis] was really difficult. I remember in the night sort of going to bed and just crying myself to sleep, not so much because I was sad but more because I was frustrated, because you feel like you're constantly saying the same thing and no-one's listening to you, you know?

Carer

Lack of joined up working [by health services] seriously impacts my mental health, causing stress, anxiety and physical health symptoms... Things get left so long the child then gets worse actually causing more pain and heartache, and effectively costs more money.

Carer

Parents/carers have the additional burden of worry about their child's wellbeing: more than 95% felt that worrying about their child's quality of life and emotional wellbeing affected their own mental health.

I guess I could see a situation in 10, 15 years' time where he has no hope, he's in pain all the time, why would he want to carry on living?

Carer

But when he has a seizure, he'll have one for like, I don't know, say it was eight minutes, and then he just goes to sleep for hours and then he'll wake and then he'll have another one and go to sleep and that'll go on for days and it just upsets me because I think that's no life for anyone, you know, it's so unfair.

Carer

'It's all in your head' – mislabelling and misdiagnosis

Our study has confirmed that rare disease patients and carers, while struggling to obtain a diagnosis, are sometimes being 'mislabelled' as neurotic or having health anxiety, and there are cases of people being misdiagnosed with serious mental health conditions. People with previous mental health issues are particularly vulnerable to mislabelling and misdiagnosis

because it can be even harder to get recognition for their physical symptoms. Mislabelling and misdiagnosis can add to the delay in reaching a diagnosis for a rare disease (and can therefore delay the start of appropriate management and treatment) and this can negatively impact on an individual's mental health. Such experiences can also prevent individuals from seeking help for physical or mental health concerns.

What I struggled with was because he was like a newborn baby I guess, I felt like the GP particularly and the health visitors thought that I was just a neurotic parent... and that was really, really frustrating because I just knew...they were wrong, you know, but if I tried to explain that to them they [would] just look at me as if to say 'what do you know', you know?
Carer

Once you have had a past mental health issue...the medical people constantly bring it up...When I have attended the doctors black and blue from falling they have even refused to examine me saying they can't treat something that does not exist.
Patient

You get to the point where sometimes you don't even want to see a doctor anymore because it's the fear of being ridiculed and being labelled, you know, as somebody that 'it's all in your head' basically, when you know it's not, and you can actually see the symptoms and feel the symptoms happening.
Patient

Looking after mental health and wellbeing

Patients and carers shared with us a range of coping techniques that they find have a positive, protective effect on their mental

health and wellbeing. They range from relaxation techniques, crafts and writing to physical activity and getting involved in research. What is actually possible and effective for an individual is highly personal and it is important to acknowledge the physical constraints and limited time that patients and carers can face.

I have recently started to use an app on my smartphone to help me be more mindful and to practice meditation which helps me to feel calmer and more in control of my emotions.
Patient

I got myself a notebook and I just wrote things down...I needed to say this stuff but there was no-one to say it to – that I was willing to say it to – but it had to come out because I couldn't deal with it anymore...and when I shut the notebook I would sit and I would just cry, because it felt better, even though I hadn't [verbally] said it.
Patient

Exercise is very important to the management of my emotional health. When I am too ill to undertake exercise, I find it incredibly difficult to deal with the symptoms as my stress levels increase without exercise.
Patient

Walking has been the only exercise I've been able to manage. Getting a very active dog has helped my motivation.
Patient

I've taken part in a number of research programmes, I've given any number of bits of my blood and skin to medical research. I've done some psychological tests. I've done all sorts...as part of wider medical research programmes into [my rare condition]. So that's been another [emotional] outlet.
Patient

EMPOWERING RARE DISEASE HEALTHCARE PROFESSIONALS

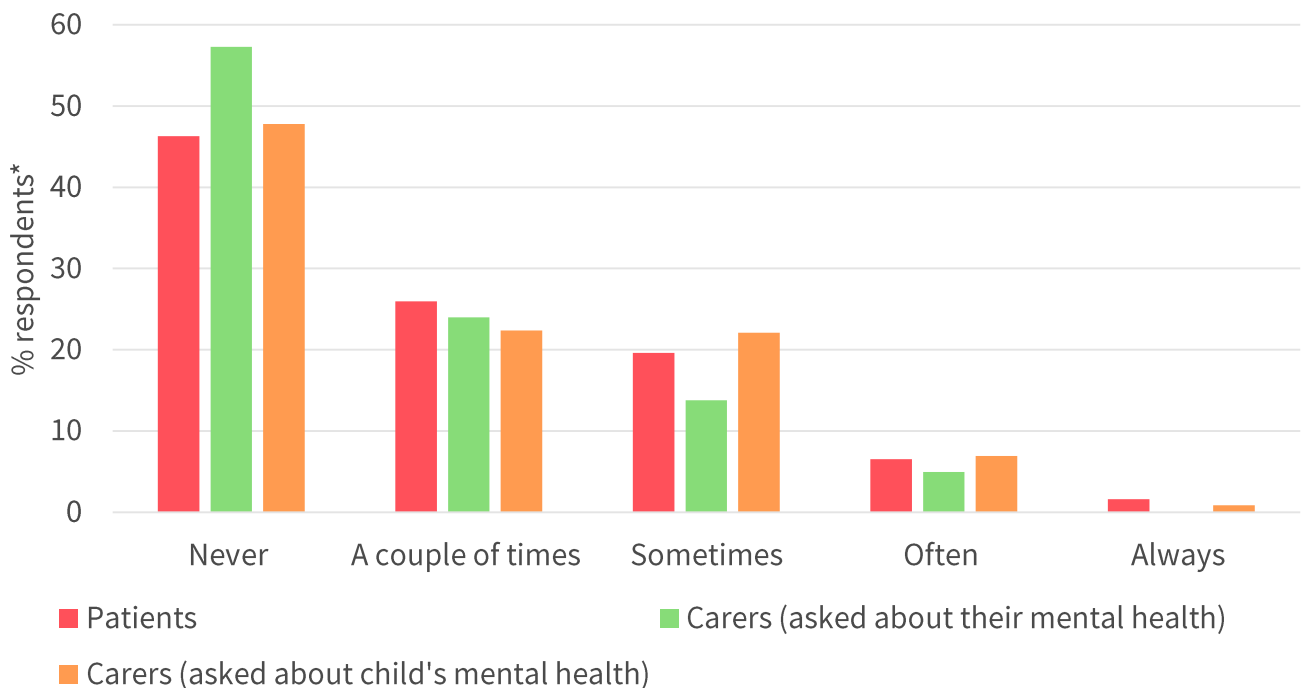
Patients and carers feel that many healthcare professionals do not demonstrate an awareness of the emotional impact of having a rare disease, or of caring for a loved one with a rare disease.

Patients and carers feel strongly that better awareness among healthcare professionals of the emotional challenges of living with a rare disease would improve their emotional wellbeing (91% of 1,314 survey respondents

who answered this question agreed or strongly agreed).

Just recognising that this is going to be difficult for people to have to deal with, no matter who they are, where you're from and what your background is, it's a big deal and just having that support to come to terms with it when you get your original diagnosis, you know.
Patient

How frequently do healthcare professionals ask about my/my child's mental health?



*of all respondents that provided an answer to this question (total number of patients = 994, total number of carers = 362/363, respectively).

Patients and carers affected by rare diseases are rarely asked about their mental health by healthcare professionals: around half are never asked.

Rare disease patients and their carers often attend many healthcare appointments due to the chronic and complex nature of their rare disease. They experience anxiety, stress, emotional exhaustion and suicidal thoughts; from diagnosis, to managing day-to-day and thinking about the future. Despite this, 46% of patients and 57% of carers reported never being asked by healthcare professionals about their mental and emotional wellbeing, and 48% of carers reported never being asked about their child's mental health.

I've been in many hospitals, I've had many specialists, I've had many GPs and I don't think any of them have ever turned round to me and said 'Nicholas³, are you suffering mentally from this? Is there anything we can do for you?'... I don't think I can even admit to having one conversation along those lines.

Patient

Patients and carers overwhelmingly felt that being asked more frequently about their wellbeing and mental health by their healthcare professionals would improve it (82% of respondents agreed or strongly agreed).

They've no idea how I've dealt with it, whether I'm dealing with it at all, I could be quite happily coming in on that day and putting the face on for them and they think everything's fine when it really, really isn't. But they don't ask. So they need to. Somehow they need to ask. Because some people aren't coping.

Patient

Well handled interactions are a great source of relief to rare disease patients and carers; insensitivity, however, can lead to distress and a reluctance to seek help for mental health concerns.

When patients and carers are given the opportunity to discuss their mental and emotional wellbeing with healthcare professionals, it can have a positive impact: 24% of survey respondents agreed or strongly agreed that a discussion had had a positive impact; 35% that discussions were handled sensitively, and 34% that discussions felt genuine.

It was like [my doctor had] given me permission [to have these feelings]... And it was great. And- I went off to the hospital that day for my treatment and it was like, OK bring it on, let's do this. And it felt better, not great, but it felt better because I understood, it made more sense to me, whereas before it was just chaos.

Patient

Unfortunately patients and carers can be negatively affected by talking about their mental health with healthcare professionals. The survey showed that 34% of respondents agreed or strongly agreed that their discussions with healthcare professionals made them feel worse, 37% that they felt uncomfortable, and 44% that they felt anxious

But the waiting list to see a counsellor on the NHS is like years. ... and the doctor I saw said 'well I could refer you now to see a counsellor... but you could have opened a vein [self-harmed] by then!' [and] after I thought, well I wouldn't have, but I thought it was really unprofessional.

Patient

In considering how their care could have been improved, to better support emotional wellbeing and mental health, 85% respondents agreed or strongly agreed that improvement would come with 'Greater sensitivity amongst healthcare professionals – an understanding

³Not his real name.

that how they talk with patients/carers can affect mental health and wellbeing.’

I want people to know how awful it is and how simple it is to change things for people like me. Sometimes it’s just the manner in which a professional will talk to you. Sometimes it’s the content of what they say makes such a massive difference.

Patient

Recommendation one: Healthcare professionals should be provided with the skills, knowledge and capacity to:
 – demonstrate awareness of the emotional challenges of living with a rare disease;
 – handle discussions about mental health sensitively.

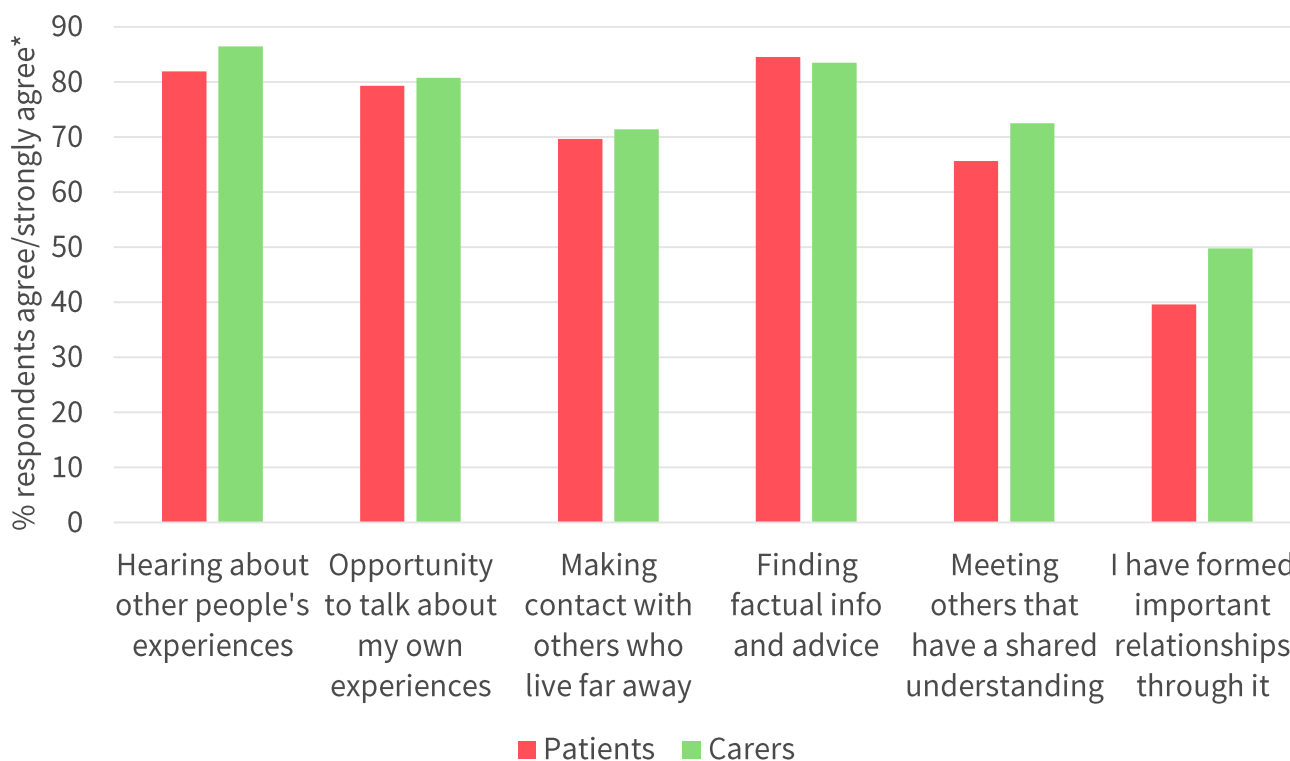
Target: Departments of Health, Health Education England NHS Education for

Scotland, Health Education Wales, Department of Health Northern Ireland, NHS England, NHS Wales, NHS Scotland, NHS Northern Ireland, college of medicine and medical schools.

Sources of support such as charity and peer group networks are highly valued but patients are frequently not made aware of their availability.

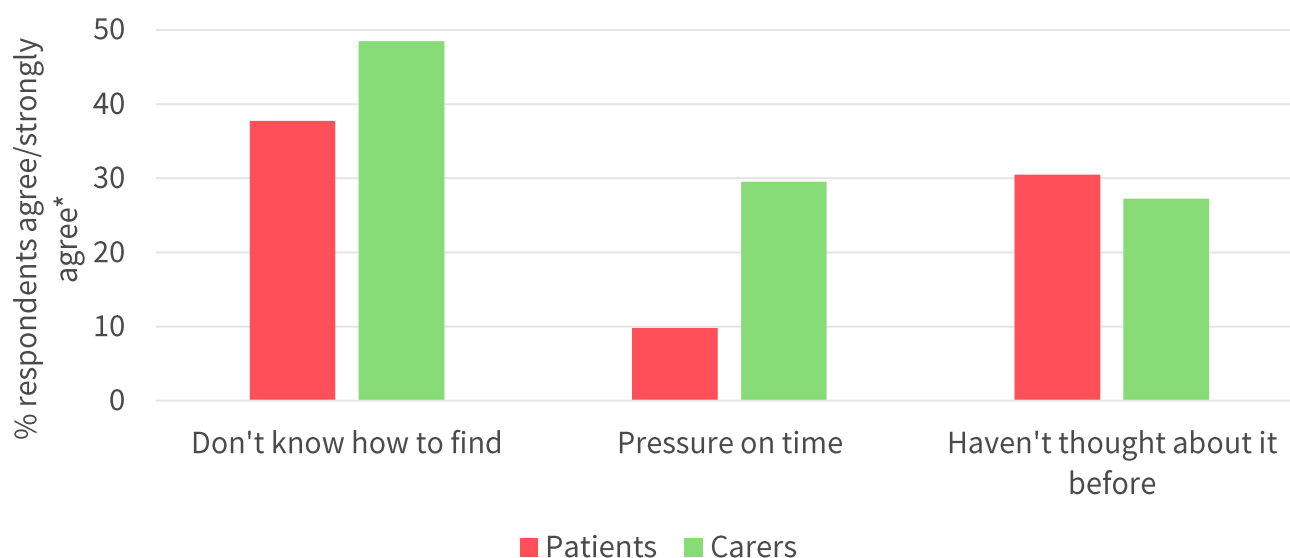
Sources of support outside the NHS, such as online and face-to-face peer or charity support groups, are valuable to patients and carers for a variety of reasons. For example, many find it helpful to hear about the experience of others in similar circumstance, to be able to talk about their own situation and to seek out factual information (see chart below).

How has support from online and face-to-face peer or charity support groups been helpful to you?



*of all respondents that provided an answer to this question (total number of patients = 547, total number of carers = 214).

If you have not accessed online and face-to-face peer or charity support groups support, can you explain why?



*of all respondents that provided an answer to this question (total number of patients = 387, total number of carers = 132)

Despite the value of online and face-to-face peer or charity support groups support, 41% of survey respondents had not accessed any of these resources. The most common reasons were that people didn't know how to find them, there is too much pressure of time (particularly for carers), and many people simply hadn't thought about it. Of those who had accessed this kind of support, the majority had not been signposted by a healthcare professional but had found it themselves (78% of patients and 68% carers). Signposting by healthcare professionals would go a long way to address these barriers to accessing valuable support.

Reflecting these findings, most respondents (70%) were unsatisfied or very unsatisfied with the information they had received from healthcare professionals about such sources of emotional support, and 85% of patients and 90% of carers felt that better signposting would help improve their wellbeing and mental health.

You need somebody to talk to [and] to give you the information as to where to go... like go to

your GP or... Samaritans or somebody like that... but you definitely do need somebody at the very start to sort of be there, to be your talk buddy or somebody, definitely. It's all those emotions that you're going through at the very start, you know, because they're all so overwhelming.
Carer

Recommendation two: Patients and carers should be routinely signposted to sources of support by healthcare professionals.

Targets: To make healthcare professionals aware of the need to deliver this: Department of Health, Health Education England NHS Education for Scotland, Health Education Wales, Department of Health Northern Ireland, NHS England, NHS Wales, NHS Scotland, NHS Northern Ireland, colleges of medicine, medical schools.

Commitment from Genetic Alliance UK: to seek funding to pilot and design a programme to develop training and resources for rare and genetic condition patient support groups to play a role in supporting the mental health needs of their community.

INTEGRATING MENTAL HEALTHCARE WITH RARE DISEASE SERVICES

There is a high level of need but mental health provision is rarely coordinated with other rare disease care despite an acceptance that multi-disciplinary team working is desirable in rare diseases.

The gold standard for rare disease healthcare is generally held to be coordination through multidisciplinary team working. We recommend that assessment of patient and carer mental health, and provision of support services, should be part of this coordinated care. The rationale for this recommendation is two-fold: 1) our findings point to problems with access to, and effectiveness of, mental health services for rare disease patients and carers, and 2) as with mental health services in general, rare disease patients and carers identify a lack of parity of esteem with physical health services.

We propose that the most efficient route to improving mental health service provision in rare diseases is to commission it as an integral part of rare disease care.

Rare disease patients and carers feel strongly that access to professional psychological support should be made easier, and that there is much room for improvement in quality and tailoring.

A large majority (85%) of survey respondents reported that access to psychological support is not as easy as it should be, and that easier access would improve their wellbeing.

54% of our respondents have not accessed any source of professional psychological support. Fully 18% of the patients and carers who *had* received some kind of professional psychological support had gone private, spending over £500 each in the majority of cases totalling at the very least £29,000 to date. Almost a third of respondents (29%) reported that they were unable to afford private therapy.

I phoned [a mental health helpline] over a year ago and because they said they couldn't come to the house and I have to stay away from people in the winter because of my [conditions] they put me through to another [charity]... they wanted £35 travel expenses to come to see me... and I just thought you can't do it, you just can't do it. So I left it and left it, until I was really, really bad.

Patient

Our findings also indicate room for improvement in tailoring of psychological support services. When patients and carers had accessed psychological support, only 49% found it helpful and only 37% felt it was tailored to their needs (agree or strongly agree). This compares favourably with the general public's experiences of psychological support; a greater proportion of people affected by rare disease found this support helpful compared to the general public. This nevertheless shows an unmet need.

Our respondents' rating was more likely to be favourable if the support had been accessed through a specialist clinic. And only 34% felt confident that they would be able to access further support again in the future, with the most confident being those who had received their care through a specialist clinic.

It was such a relief for someone to understand and take it on-board, [the therapist had] even gone and done a little bit of research on [my condition]... it was like, you know: "oh someone's listening, someone's listening."

Patient

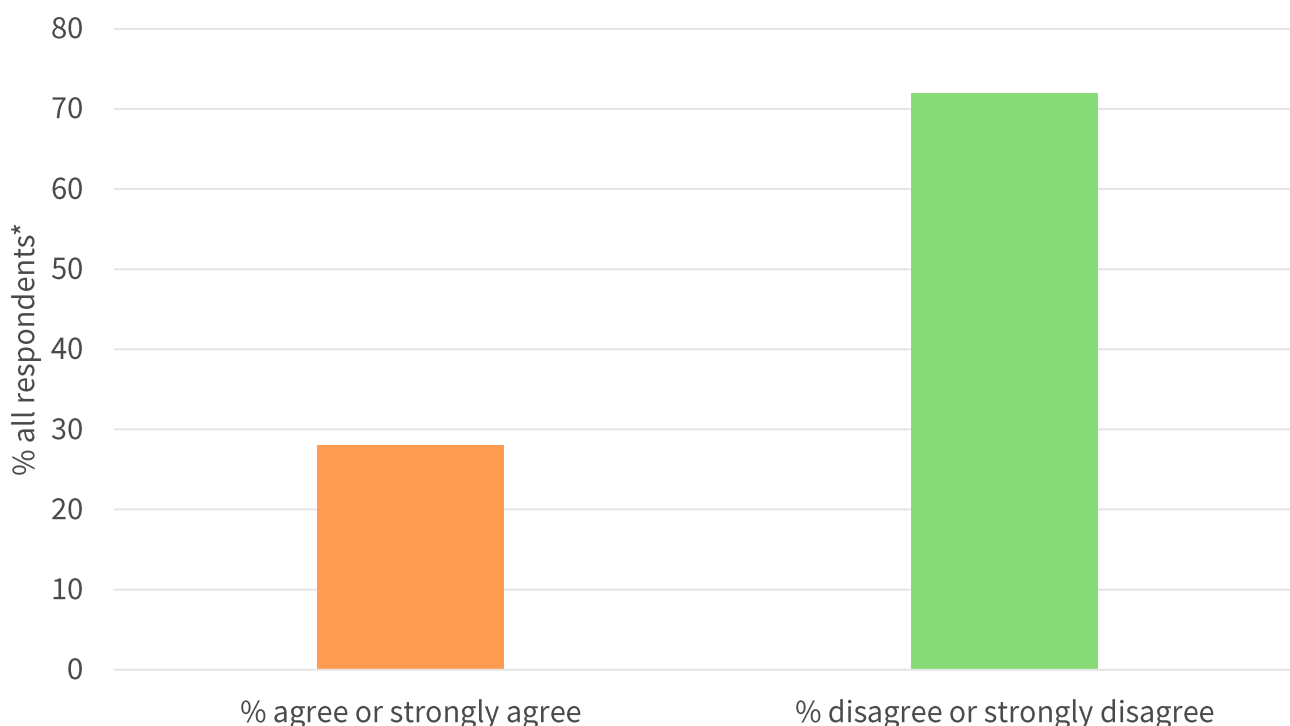
It's actually really helpful because anything that makes us function more effectively as a [parenting] team and supports us to develop a better joint understanding and joint approach makes it better for Oscar and, in the end, makes

it better for the medical people that are working with him as well because the more we can do effectively, the better for everybody really.
Parent

Rare disease patients and carers reported that their mental health was not considered as important as their physical health, and vocalised a significant unmet need for person-centred, coordinated care.

We asked survey respondents whether they believed their, or their child's, emotional health is treated as equally important as their physical health. Over 70% disagreed or strongly disagreed, and this holds for both patients and carers.

Those that believe their / their child's emotional health is treated as equally important as their / their child's physical health



*of all respondents that provided an answer to this question (total number of respondents = 1135).
When healthcare professionals talk to rare disease patients and their families about mental health, it can lead to referrals to mental health services (29% of patients and 23% of carers reported that, if they did have a conversation about their mental health, it led

to a referral). Yet our survey showed that around half of patients and carers have *never* been asked about their mental health.

Findings from both our interviews and survey suggest that a lack of tailored care that focuses on the specific needs of individuals is a major problem.

It's taken a long time for us to get the doctors to look at anything other than his physical wellbeing.

Carer

The communication between psychiatric services and medical services... I don't think it's very good... I kind of feel like it's a tug of war.

Patient

Interviewees made specific suggestions about how mental health care should be coordinated in order to improve the support they receive.

If [mental health] services are available and accessible, provide information about them there and then because we would then look at that and decide we need that... I think my advice would be introduce it as early as possible at the same time as you talk about the physical health related things and then let people come to it.

Patient

Recommendation three: Coordinated rare disease services should include assessment of mental health needs and access to mental health services. This should be extended to carers.

Target: NHS England, NHS Wales, NHS Scotland, NHS Northern Ireland, Rare Disease Advisory Group.

LOOKING AHEAD

This report is the first of its kind, no comprehensive study looking at the relationship between mental health and rare diseases has been carried out before. We have found that living with a rare condition can have a huge impact on emotional wellbeing and mental health.

We know that mental health challenges are not just exclusive to rare diseases, and that the chronic underfunding of health services means that we are working to make improvements in an already constrained environment. The recommendations in this document however, if effectively implemented, will begin to address some of these issues.

This report will be launched in Westminster and delivered to the Parliamentary Under Secretary of State, Steve Brine MP, on the same day. We will work with parliamentarians and policy makers to ensure that mental health is considered as important as rare disease patients' and carers' physical health.

Genetic Alliance UK, the national charity that runs the Rare Disease UK campaign, will do its part. Subject to funding, Genetic Alliance UK will pilot and design a programme to develop training and resources for patient support groups to support the mental health needs of their community.

ANNEXES

Annex one: Finding the right support

If you would like to talk to someone about your mental health, in the first instance you should contact your GP. There are also other avenues available:

Mental health support

Samaritans offers free, confidential, 24-hour emotional support over the phone (116 123) or by email (jo@samaritans.org), or face-to-face at your local branch:

www.samaritans.org/branches

Mind, the mental health charity, offers information about mental health and accessing support on their website (www.mind.org.uk/). They also provide information over the phone (0300 123 3393), by email (info@mind.org.uk) or by text (86463).

Mind has also launched a 'Find the Words' campaign. This aims to support individuals in talking about mental health with their GP:

www.mind.org.uk/findthewords

Carers UK also offers a free helpline (0808 808 7777) that offers advice on financial and practical matters related to caring, as well as a listening service. They also provide a free online carers forum: www.carersuk.org/forum

Other sources of support

Our parent charity Genetic Alliance UK is an alliance of over 200 patient organisations, many of which are condition – specific UK charities and exist to support children, families and individuals living with a genetic condition, many of which are rare. They are the experts in

understanding their specific conditions and at providing the support that patients and carers need.

Genetic Alliance UK's [members' webpage](#) has a 'search' function, where patients and carers can find support groups that may be relevant.

Patients and carers may also be able to find a support group by searching the name of the condition and the words 'patient support UK' on Google.

What if there isn't a UK support group for my condition?

Where there isn't a specific support group for a rare condition, there may be an 'umbrella' organisation that can provide support. For example, there are support groups for patients with metabolic disease, or conditions that affect growth, that cover many different specific conditions. Healthcare professionals may be able to help patients or carers decide what type of category, and therefore which umbrella organisation, a condition might fall under.

The internet can also provide a wealth of virtual areas for people to meet and talk about their experiences with rare disease. For example:

Facebook

There are a growing number of informal online support groups available on Facebook. You don't need to have a Facebook account to search for groups – although if you do find a relevant group you will need to sign up to join and talk to people.

If there isn't a Facebook group, there is the option of setting up a group, so that others will be able to find you in the future.

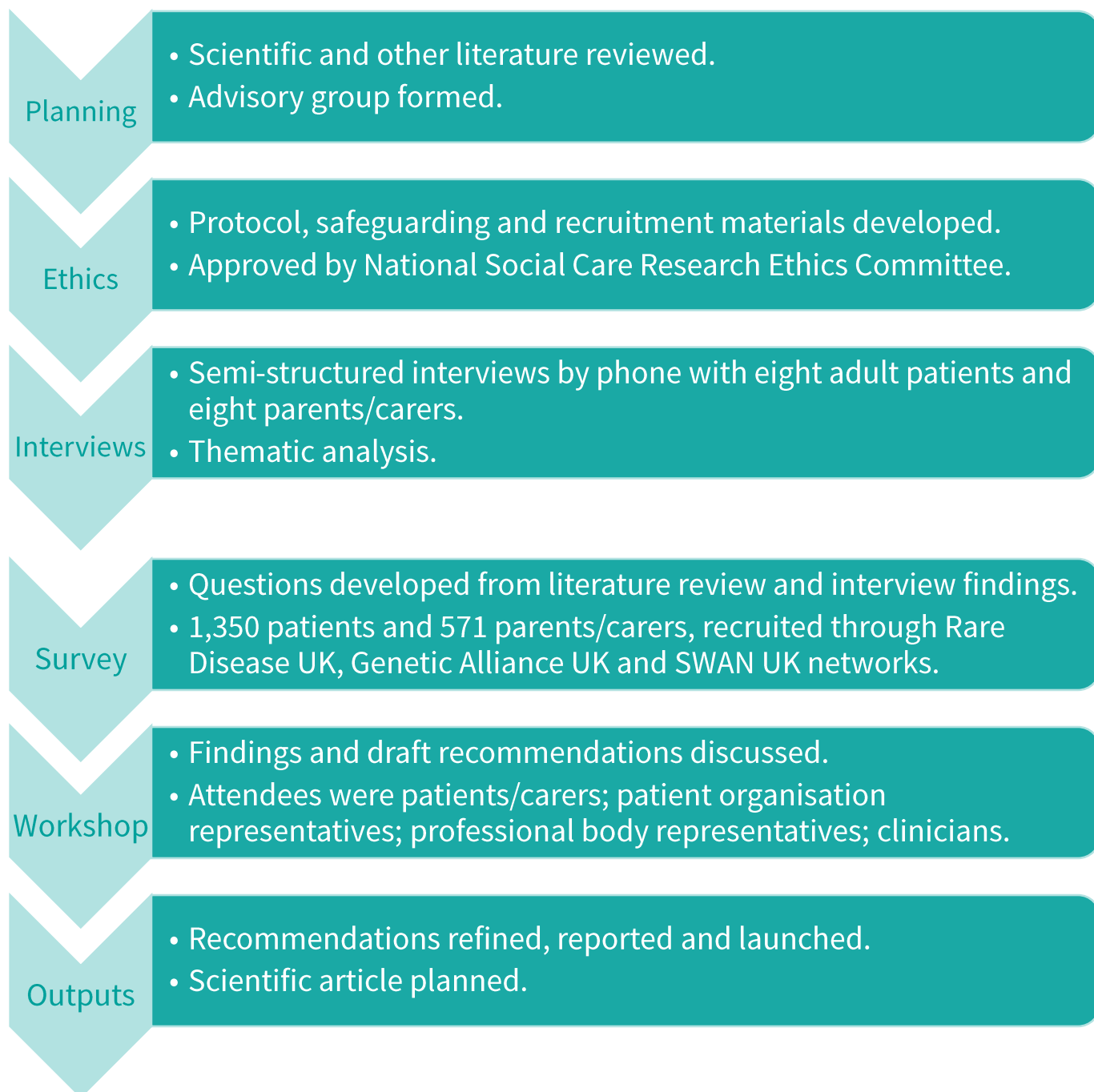
RareConnect

[RareConnect](#) is another free online platform that aims to connect individuals affected by rare disease across the world. RareConnect has disease – specific communities and general discussion groups. The platform was set up by

EURORDIS, an alliance of rare disease patients in Europe. Discussions are translated across six languages (English, French, German, Italian, Spanish, and Portuguese).

If you would like help setting up a support group for your condition, please see the page on Genetic Alliance UK's 'Building Rare Communities' project on Genetic Alliance UK's website.

Annex two: Study Method



Annex three: Advisory group membership

Name	Occupation	Organisation
Helen Dennehy (from 1 August 2017)	Parent of a child with a syndrome without a name	SWAN UK Parent Representative for Nottingham, Oxfordshire and Berkshire
Rebecca Nunn	Rare disease patient/ medical student	University of Cambridge
Jane Swainson	Rare disease patient	Rare Disease UK management committee
Celine Lewis	Senior Research Social Scientist	GOSH and UCL Institute of Child Health
Jacob Diggle	Research and Evaluation Manager	Mind
Richard Lynn	Clinician (psychology)	Royal College of Paediatrics and Child Health, and Rare Disease UK management committee
Larissa Kerecuk	Clinician (paediatric nephrology)	Birmingham Children's Hospital, and Rare Disease UK management committee
Farhana Ali	Public Affairs Manager	Rare Disease UK, Genetic Alliance UK

Annex four: Workshop attendance List

Organisation

Representative of University College London Hospitals NHS Foundation

Representative of Genetic Alliance UK

Representative of Multiple System Atrophy Trust

Representative of Centre for Mental Health

Representative of Welsh Health Specialised Services Committee

Representative of SWAN UK

Representative of Mind

Representative of Batten Disease Family Association

Representative of Rare Disease UK

Representative of AKU Society

Representative of University of Reading

Representative of Royal College of Paediatrics and Child Health

Representative of Ataxia UK

Representative of South London and Maudsley NHS Foundation Trust

Patient representative

Representative of Nursing and Midwifery Council

Representative of Mental Health Foundation

Representative of Unique

