

Communication Strategy 2021



Developed in collaboration with OPEN Health Communications

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Introduction

Spotlight YOPD is a UK-based charity with the ultimate goal of supporting patients with young onset Parkinson's disease (YOPD), raising the profile and mobilising research into YOPD. Spotlight YOPD have five aims to help achieve their overall vision. These aims have formed the structure of this communication strategy.

Spotlight YOPD's aims and vision

Vision: Shining a light on better living now with young onset Parkinson's (YOPD) and researching for a brighter future

Aims:

- Ensure YOPD is recognised globally as a rare (often genetic) syndrome that requires focussed research
- Mobilise genetic testing ensuring YOPD patients have an effective diagnosis leading to better care
- Deliver campaigns so YOPD families have access to research, innovative treatments and other emotional, practical and financial support
- Have YOPD recognised in guidelines enabling holistic disease management at every stage of life
- Accelerate diagnosis and empower patients and families to take control of the condition

Spotlight YOPD word cloud

In preparation for writing this communications plan, OPEN Health gained expertise from Spotlight YOPD in an interactive workshop. The 'word cloud' is a collection of idea, themes and terminology.



Aim 1: Ensure YOPD is recognised globally as a rare (often genetic) syndrome that requires focussed research

Current landscape

Parkinson's disease (PD) is a relatively well-known condition across the globe, but many people have never heard of YOPD. YOPD is clinically, pathologically and genetically distinct from PD. YOPD is in a unique group, which requires a tailored multidisciplinary approach to management, assessment, treatment and support. Moreover, YOPD is often misdiagnosed, undiagnosed and stigmatised due to the lack of awareness and understanding. We need to change perception, address the knowledge gap and encourage research in YOPD.

Need for change

Improving the understanding of YOPD is imperative to supporting YOPD patients. In the UK, NHS advice and The National Institute for Health and Care Excellence (NICE) PD guidelines fail to acknowledge YOPD, highlighting the need to drive recognition even among the medical community. YOPD has an underlying genetic component and therefore there is a need to increase research into genetic testing so that patients can receive an earlier diagnosis. Current research in YOPD is often driven by YOPD patients themselves, who already suffer the burden of disease. Recognising YOPD globally can support patients throughout their journey and support healthcare professionals (HCPs) to provide suitable, holistic and appropriate treatment.

Key audiences

There are several key audiences to target when it comes to YOPD support. These include the general public (including hospitals), YOPD patients categorised by age (under 26 and over 26 years old), carers (family/ friends), HCPs (general practitioners [GPs], neurologists, geriatricians, rare disease experts etc.), government and sponsors. These stakeholders all have a critical role to play in caring for YOPD patients, and it is important that we expand our outreach using social media to raise awareness.

What points need to be covered in our communications?

- YOPD for beginners: The differences between YOPD and later-onset PD for those who are unfamiliar with the disease background
- Psychological, emotional and social impacts on relationships, employment and finances in newly diagnosed YOPD patients
- How the following factors implicate YOPD management in different settings:
 - Circumstances and societal engagement
 - Genetics
 - Clinical aspects
- How effective are the different multidisciplinary approaches for YOPD care, and how can they be improved moving forwards?

What will success look like?

- Increased awareness of YOPD among neurologists and geriatricians, measured by verbal feedback in response to supplied information
- Increased outreach to the general public; may be measured through social media engagement from non-YOPD followers
- Uptake and spread of provided information by hospitals and universities
- Acknowledgement of YOPD on the NHS website
- YOPD covered on the agendas of global PD congresses

Suggested tactics

Stakeholder	Recommended tactic
Physicians (neurologists/geriatricians)	<ul style="list-style-type: none"> • Educational email on YOPD, driving HCPs to Spotlight YOPD's website • A5 digital flyer with key information on YOPD and distinction from PD
University lecturers (life science)	<ul style="list-style-type: none"> • Email inviting lecturers to incorporate YOPD into relevant learning modules and dissertation topics
General public	<ul style="list-style-type: none"> • Engaging educational content pushed through social media channels, such as TikTok, Instagram and Facebook. Video shown to be most effective medium • Leavepieces and posters in hospitals

Aim 2: Mobilise genetic testing ensuring YOPD patients have an effective diagnosis leading to better care

Current landscape

YOPD is notably different to PD, partly due to the genetic aetiology. Individuals who have both YOPD and a family history of PD are more likely to carry mutations in certain genes associated with the disease. Gradually, more and more research is investigating the link between YOPD and genetics.

Until recently, a combination of reasons caused a reserved attitude towards genetic testing in PD and YOPD. These include the lack of therapeutic consequences of an identified PD gene mutation and clinical variability between and within genotypes. There are some important issues that make genetic counselling a very challenging area, particularly in terms of risk predictions for family members and their offspring. The advantage of an identified PD gene mutation in the diagnostic process of YOPD is limited to those with a very early onset (especially a juvenile onset) and those with complex or atypical phenotypes. Nonetheless, genetic testing can have great prognostic value; the identification of a mutation might allow some predictions on the further evolution of the disease. Genetic testing is currently available for the following genes related to PD: *GBA*, *PARK7*, *SNCA*, *LRRK2*, *parkin* and *PINK1*.

Need for change

The diagnosis experience is emotional, scary and life-changing. People living with YOPD can have a longer journey to diagnosis, sometimes seeing multiple doctors and undergoing several tests before reaching a conclusion. Utilising genetic testing to identify gene mutations can aid a faster diagnosis, which will end any further diagnostic challenges related to the complex differentiation of YOPD.

Many gene-specific interventions are now entering clinical trials, such as genetic testing for *GBA* and *LRRK2*. Some YOPD patients are aware of these developments through the internet and social media, and want genetic testing done for this reason. There are also recent suggestions that gene status might also affect outcome of deep brain stimulation in PD, which has fuelled an interesting area of research known as 'surgicogenomics'.

Despite the benefits, many people with YOPD are unaware of the importance and implications of genetic testing. Emerging therapeutic implications for specific genotypes will be an important driver that will change the attitude of patients and HCPs towards genetic testing.

Key audiences

People living with YOPD and HCPs are the key stakeholders to think about when considering communications around mobilising genetic testing. Education and awareness among the YOPD community is imperative to highlight the importance of genetic testing in diagnosis and treatment outcomes.

Genetic testing needs to be considered as an option for physicians in everyday clinical practice to support diagnosis and prognosis for YOPD patients. The multidisciplinary team should be encouraged to work together to discuss options when a patient presents their symptoms.

What points need to be covered in our communications?

- A summary of key studies and data on genetic testing for diagnosis of YOPD and the implications of genetic testing
- An overview of the current genetic counselling advice
- Education on genetic counselling and the implications of genetic testing using a central resource available for patients and HCPs
- Guidance for HCPs on how to implement genetic testing for YOPD, including genetic counselling
- Recommendations for how to obtain reliable genetic testing
- Recommendations for healthcare centres and companies to ensure the testing covers clinical aspects, counselling dilemmas and genetic pitfalls of testing the genes associated with YOPD and PD
- Impact of a faster diagnosis on the emotional wellbeing for people with YOPD
- Genetic testing to support treatment outcomes

What will success look like?

- Increased knowledge and understanding of genetic testing among YOPD community, neurologists, GPs and geriatricians, measured by verbal feedback in response to supplied information
- Uptake of genetic testing for YOPD diagnosis
- Inclusion of genetic testing in all YOPD guidelines and support materials
- Increased funding into genetic testing and more research, measured by availability of literature on genetic testing

Suggested tactics

Stakeholder	Recommended tactic
YOPD community	<ul style="list-style-type: none"> • Informational leaflet/brochure containing an overview of genetic testing and outlining the benefits
HCPs	<ul style="list-style-type: none"> • Communications tool with the key findings from recent genetic studies on YOPD
HCPs and pharmaceutical companies	<ul style="list-style-type: none"> • Educational training programmes for the multidisciplinary team on genetic testing
Pharmaceutical companies	<ul style="list-style-type: none"> • Emails and letters to pharmaceutical companies encouraging them to fund research into genetic testing
University lecturers (life science)	<ul style="list-style-type: none"> • Email encouraging universities to incorporate genetic testing education for PD and YOPD in medical school curricula

Aim 3: Deliver campaigns so YOPD families have access to research, innovative treatments and other emotional, practical and financial support

Current landscape

People living with YOPD are often managing careers, raising families, or juggling both at the time of diagnosis. Finding time to take an early, active approach to managing YOPD care can seem daunting, but it is essential. This is why raising awareness for YOPD has gradually become more important: so that YOPD families feel supported by the wider community, and in turn may have better access to research, innovative treatments and other emotional, practical and financial support systems.

The benefits of early intervention for those diagnosed with YOPD can positively influence outcomes. Younger brains have greater neuroplasticity, so they have the ability to grow and change in response to therapy. By developing an understanding of what is happening in the body and the brain, the available treatment options and some of the unique features of having this disease at a young age, YOPD patients will have a better foundation for making important healthcare decisions now and in the future.

Need for change

Recent studies highlighting several different YOPD conditions and how they affect quality of life (QoL) highlight the importance of a multidisciplinary approach in managing the care of patients with YOPD and their families. The importance of the emotional aspects that come with caring for a patient with YOPD should never be overlooked.

YOPD occurs at a time when young people already have a very full life. Managing career and family obligations along with the stress associated with the presence of a chronic disease can prove to be a challenge to all members of the family. For some, the most difficult aspect of YOPD is an uncertain future.

Many find comfort in communicating with others who are living with YOPD. It is vital that YOPD support groups, online discussion groups and various programmes are put in place to give YOPD patients the opportunity to meet and to share information and resources with other young people and their families. Professional counselling can also be very beneficial. Both individual counselling and family counselling can provide a private space for YOPD patients to voice their concerns and also facilitate better communication between family members and carers so that everyone can develop healthy ways of adapting.

Key audiences

The key audiences for this aim are the wider YOPD community, HCPs, and educators. This includes neurologists, psychologists, schoolteachers, and university lecturers. It is vital that we reach out to these individuals and raise awareness of the differences between PD and YOPD as both these illnesses are confused. In addition, by raising awareness with HCPs, they will be able to distinguish YOPD patients, and by incorporating this topic in school curricula, the wider community can be alert and more understanding when YOPD patients present their symptoms and the correct support can be provided when needed.

What points need to be covered in our communications?

- An outline of campaigning strategies to increase awareness in public settings, such as in hospitals and at medical conferences. The outline should include initiatives, tactics and overall goals accompanied by value messages
- A reference bank of relevant research articles and studies for YOPD patients to access
- An overview of current and ongoing therapies, treatments and clinical trials for YOPD that are proven to be effective for maintaining a good QoL, and alternatives such as surgical treatment i.e. deep brain stimulation surgery
- A guide on the psychological, emotional and social impact that YOPD has on patients, and how to manage depressive emotions and disorders
- Recommendations for financial advisors, such as the PDS Welfare and Employment Right Department. Financial advisors can provide information regarding benefits, planning for the future to avoid financial hardships and how YOPD patients can either remain in, or re-enter employment

What will success look like?

- Increased local support groups within each region for YOPD patients, their families, friends and carers across the UK
 - More support among peers
 - Establish exercise groups for YOPD patients
 - Provide personalised information, services and opportunities to those affected by the disease
- Increased awareness and understanding of the physical, emotional, practical and financial impacts that YOPD has on patients
 - Raised awareness of the many symptoms and their distressing impacts
 - YOPD to be a part of public conversations and on the agenda for politicians and policymakers
 - YOPD patients to feel understood and become more confident in revealing their disease, knowing they will be treated well and with respect.

Any extra hints and tips?

Spotlight YOPD should familiarise themselves with information regarding the many types of grants, loans, schemes and financial support. This will allow Spotlight YOPD to provide guidance for people living with the condition. This includes information on parking schemes, help with council tax and healthcare packages that are arranged and funded by the NHS in England and Wales, and Parkinson's UK Grants.

“We may each have our own individual Parkinson’s, but we all share one thing in common. Hope.”

Suggested tactics

Stakeholder	Recommended tactic
YOPD community	<ul style="list-style-type: none"> • Create an educational environment using online and social media platforms such as YouTube and Instagram • Encourage dedicating one week to YOPD during Parkinson’s Awareness Month to increase awareness • Community gatherings/social activities for YOPD patients, such as fitness classes • Get involved with the upcoming triennial World Parkinson Congress in Barcelona, Spain, 2022. It is an international congress for basic scientists, clinical researchers, HCPs, patients with PD and others to discuss, learn and engage in debate around the latest scientific discoveries, medical and comprehensive care practices related to PD
HCPs	<ul style="list-style-type: none"> • Educational leaflets and brochures to share with YOPD patients and colleagues • Recruiting HCPs with YOPD expertise to participate in seminars and conferences
University science degree programmes	<ul style="list-style-type: none"> • Incorporate YOPD studies as a subsection of PD within curricula

Aim 4: Have YOPD recognised in guidelines enabling holistic disease management at every stage of life

Current landscape

Clinical practice guidelines are a summary of recommendations on how to diagnose and treat a medical condition and are mainly aimed at HCPs. The aim of guidelines is to ensure that patients receive appropriate treatment and care, and to standardise care across a region. There are several guidelines available in the UK to support the diagnosis and treatment of PD: key guidelines include those published by NICE and Parkinson's UK. Information on PD is also available on the NHS website.

Whilst the full NICE diagnosis and management guidelines for PD briefly discuss YOPD, the condensed guidelines displayed on the NICE website fail to mention YOPD at all. Similarly, the NHS web page for PD also does not cover YOPD. On the other hand, Parkinson's UK have a comprehensive standalone guidelines for best practice in YOPD on their website.

Need for change

Clinical practice guidelines often act as a key reference point for HCPs and support diagnosis/treatment decisions. The complete omission of YOPD in such guidelines means that HCPs (sometimes even experts in the field) are unaware of the existence of YOPD or how the treatment/diagnosis of YOPD differs from that in typical patients with PD. Incorporating exploration of YOPD in existing guidelines or developing new additional guidelines specifically for YOPD will help raise awareness of the disease among HCPs, as well as improve and standardise diagnosis and treatment for YOPD patients. There are differences between the presenting symptoms and disease progression of YOPD and typical PD, and it is essential that these are highlighted in the guidelines.

Holistic disease management involves treating the whole patient and may involve pharmaceutical intervention, surgery, physiotherapy, speech/language therapy, occupational therapy and counselling. At current, YOPD patients are often provided with the exact same treatment as patients with typical PD and are often even treated by geriatricians. This means that the differing needs of the younger patients are often not met, particularly from a psychosocial perspective. Through coverage of YOPD in the guidelines, specific recommendations for treatment can be made and therefore improve standard of care.

Key audiences

The key audiences for this aim are policymakers and those who create the guidelines. This includes individuals from NICE, NHS England and the Care Quality Commission. The websites for these bodies often have contact details, but it may be preferable to reach out to relevant individual employees directly. While the key audience for this aim is those who create the guidelines, there are also secondary audiences that can help put pressure on these bodies to update guidance. Secondary audiences include other leading PD experts (usually HCPs and university researchers), PD charities and PD patient groups.

What points need to be covered in our communications?

- A brief summary of what is covered in the existing guidelines and an explanation of why it is insufficient
- Evidence to help highlight the lack of YOPD awareness among HCPs
- Synopsis of difference between diagnosis, treatment and disease progression in PD and YOPD
- Anecdotal description of the current diagnosis/treatment experience of a YOPD patient, and how this can be improved through guideline updates

What will success look like?

- Coverage of YOPD in the condensed NICE guidelines accessed through the main NICE PD page
- More detailed exploration/separate guidelines for YOPD in the full NICE guidelines, with a particular emphasis on psychosocial care
- Acknowledgement of YOPD on NHS web page for PD
- Ultimately, the goal is to improve awareness and see a difference in the treatment of YOPD (as a reflection of guideline updates)

Any extra hints and tips?

NICE has several standing committees responsible for the development of NICE guidance, and such guidance is often discussed in a meeting with representative experts/policymakers/charities and patients. Members of the public can register to attend these meetings on the NICE website. Whilst public attendees are unable to offer opinion or participate in discussion, it may be beneficial for a Spotlight YOPD member to attend any relevant meetings and understand the conversations behind the published guidance!

Suggested tactics

Stakeholder	Recommended tactic
NICE and NHS	<ul style="list-style-type: none"> • Script for telephone calls • Email copy to outline need for guidance change (can be personalised if individual employee email addresses are identified) • Digital flyer about need for guidance change • YOPD patient experience video detailing how diagnosis/treatment guidance should differ from typical PD • Series of tweets lobbying guidance change
Secondary audiences	<ul style="list-style-type: none"> • Guidance document for how secondary audiences can apply pressure on organisations to update guidance. Would include an overview of materials for NHS and NICE

Aim 5: Accelerate diagnosis and empower patients and families to take control of the condition

Current landscape

Around 4–10% of people diagnosed with PD are under the age of 50. While treatments are the same, younger people may experience the disease differently. Patients with YOPD may have a longer journey to diagnosis, sometimes seeing multiple doctors and undergoing several tests before reaching a correct diagnosis. It is not uncommon for arm or shoulder stiffness to be attributed to arthritis or previous sports injuries.

Need for change

Quicker and more accurate diagnosis is crucial to supporting YOPD patients, with patients frequently spending multiple years in a cycle of new specialists unable to explain their pain. There is a need to get potential YOPD patients seen by a neurologist as soon as possible in order to receive a diagnosis. A faster diagnosis is also beneficial for treatment outcomes.

The emotional, social, physical and psychological needs for those diagnosed with YOPD can be extremely different to those diagnosed at a later age. Many diagnosed are rising though their career, looking to buy their first house, or maybe starting or maintaining a family. The diagnosis of YOPD for people at this stage of their life can be a very traumatic experience as they often have to re-assess and re-plan their life to accommodate for this crippling condition. Patients need to feel like they can control their disease and live their life, rather than let the disease dictate change. By enabling a faster diagnosis, this can reduce the emotional burden on people living with YOPD.

Key audiences

The key audience when talking about YOPD diagnosis is HCPs, in particular GPs, who will be the first to encounter undiagnosed YOPD patients. It is essential that YOPD can be recognised by HCPs, and as a result the patient referred correctly to a neurologist. Newly diagnosed patients will need support when discovering what their life will look like after their diagnosis.

What points need to be covered in our communications?

- Communications tool to support the recognition of early symptoms of YOPD for patients and HCPs
- Guidelines for primary care (GPs) for the process on referring patients to the correct specialist as soon as possible
- Psychological, emotional and social impact on relationships, employment and finances in newly diagnosed YOPD patients
- Advice and 'cheat sheets' on living and maintaining a balanced life with YOPD
- Positive resources for recently diagnosed patients

What will success look like?

- Faster diagnosis, measured from first presentation to diagnosis
- Increased and continued engagement from newly diagnosed YOPD patients. This could be measured through social media channels or through membership to Spotlight YOPD
- Increased openness by patients about their YOPD diagnosis
- More content available to both HCPs and patients that supports life with YOPD

Suggested tactics

Stakeholder	Recommended tactic
Physicians (GPs)	<ul style="list-style-type: none"> • A digital flyer with key information on early signs and symptoms of YOPD • Educational email on YOPD and available resources, driving to Spotlight YOPD website, Parkylife etc. • Digital toolkit for diagnosing YOPD and the key HCPs to consider
Newly diagnosed patients	<ul style="list-style-type: none"> • Informational leaflet to be given by the HCP to patients shortly after diagnosis, providing them with some additional information, positive resources and inviting them to the Spotlight YOPD community

Key audience 1: Communication with the general public

Aims

- **Education:** Educating the general public on YOPD, its symptoms, management and treatment is so important to help reduce stigma and ensure people know how to react to people with YOPD
- **Awareness:** Increasing awareness can support conversations with patients and HCPs and can further increase efforts and funding for testing, treatment and support
- **Reduce the fear:** People are afraid of what they don't know and can't understand. By increasing understanding in the general public, people will be less afraid to speak about YOPD

Identifying audience

People living with YOPD can be ambassadors for YOPD. They can and should be encouraged to reach out to their friends, colleagues, peers and family, to educate them. However, Parkie's have enough responsibilities already and we need to ensure that key stakeholders are all actively encouraging awareness among the general population. Charities, pharmaceutical companies, support groups and Parkinson's organisations need to support the education and awareness campaigns. In addition, educational stakeholders, such as university professors/department heads and secondary school teachers, can be mobilised to inspire education on YOPD in schools and universities. In the healthcare community, we can encourage organisations within healthcare, such as healthcare agencies, to host an annual YOPD day and YOPD fundraiser.

Audience background

Many people have never heard of YOPD and people automatically assume it is an 'older person's' disease. The most important thing we can do for YOPD is normalise it, discuss it and encourage everyone to see the full picture of YOPD. Following discussions to gain insights from people with YOPD, it is apparent that the general population can mistake YOPD symptoms with drunkenness. People with YOPD can feel stressed when they show symptoms in public, which in turn worsens their symptoms. This can affect their balance, causing them to stagger and slur their speech, giving the impression that they're drunk. Increasing awareness with educational tools can help the general public to better understand the disease and reduce the stress that people with YOPD face.

Key platforms

Social media is a key platform for reaching out to the general public, particularly young people. Campaigns that are targeted to young people can help better understand YOPD and reduce stigma. Facebook, Instagram, TikTok and Twitter can be powerful tools to engage young people and increase awareness of YOPD. Videos have been shown to be the most powerful medium for conveying information via social media, so TikTok can be transformational in raising the profile of Spotlight YOPD.

Ambassadors are vital to raising the profile of YOPD and big names have already been talking about YOPD in public. These include Michael J Fox and Orlando Bloom.

Educational hubs can be valuable for anyone looking to find out information on YOPD. Having a hub to provide information on symptoms, genetic testing, management and treatment may help support and deepen understanding in the community. Key educational hubs include:

- Spotlight YOPD website
- Parkinson's Foundation
- World Parkinson Coalition
- Michael J Fox Foundation
- John Hopkins Medicine
- ParkyLife

Tone and messaging

Communications with the general public should encourage people to talk about YOPD and to not be afraid to ask questions to help educate themselves. The tone should be light but educational and ensure they can understand the disease

Spotlight YOPD aim to convey the following values to everyone using our platform:

- Inclusive
- Non-judgemental
- In solidarity
- With resolve
- Person-centred
- Holistic
- Quirky
- Focussed/specialist/expertise

Key terminology

The correct terminology can be confusing for the general public as you do not want to cause offence or appear rude. For example, the term 'Parkies' might be appropriate for interactions with those living with YOPD but some people will find that term offensive. Always ask the individual what their preference is and ensure you're both comfortable.

Key terms that may be used:

- People with Parkinson's (PWP)
- People with Young Onset Parkinson's Disease – People with YOPD
- Some people with YOPD like to be called 'Parkies'

“Humanise the Parkinson’s experience for the general public – and let people know we are not just drunks staggering around!!”

Matt Eagles, YOPD role model

Key audience 2: Communication with family members and carers

Aims

- **Providing emotional support:** The patient and his or her family members are likely to experience a wide range of emotions as they try to manage this unexpected change in their lives. Individual counselling can provide a private place for a YOPD patient to talk about the impact PD on their personal lives and family, but family counselling can also facilitate better communication between all family members and help everyone develop healthy ways of adapting.
- **Guidance on how to support YOPD patients:** Proper training and guidance must be given to the family members and carers of newly diagnosed YOPD patients. This will be a pivotal role in the life of a YOPD patient, and the appropriate care needs to be given to accommodate the challenges, which vary from patient to patient.

Identifying audience

Family members and carers can belong to the various categories such as parents, siblings, spouses and professional caregivers. It is important to acknowledge that in most cases these individuals must support YOPD patients physically, emotionally and financially. This can lead to strain on the mental health of the carer, as well as lead to family conflicts. Some challenges that family members face are sleep deprivation, communication challenges and emotional turmoil. At some point, a loved one may get a great deal of benefit from having a professional caregiver help with everyday tasks.

Audience background

The role of a family members or carers of YOPD patients will ultimately be focussed on patient care and support. This role can be draining and create conflicts between family members if not managed properly. One family member or carer may feel alone in providing care and lash out at other members, while another may not think financial or medical matters are being handled correctly. Others might disagree with the level of care being provided. The different perspectives and opinions may lead to disputes among family members. These conflicts may even cause stress for the YOPD patient. Therefore, families must find a way to hear each other, cooperate and establish a plan that all find acceptable.

Key platforms

In the age of social media, platforms such as Instagram, Facebook, Twitter and even TikTok are most popular for engaging with YOPD patients and their family members and carers. Digital strategies are vital in campaigns to raise awareness of YOPD prevalence within our communities. These platforms can be used to reinforce information or sentiments about YOPD within the community and provide support for the family members and carers of YOPD patients. It also allows patients to network and interact with other YOPD patients globally to feel a sense of belonging and unity.

Tone and messaging

The tone of communication with family members and carers should be light, compassionate and empathetic. Family members and carers also need emotional support as it can be a very difficult to cope with the stress and anxiety of a close family member or friend being diagnosed with YOPD. Caring for the patient can also be an exhausting experience, so it's important to be gentle with the way messages are conveyed.

It's important to consider the following when speaking to family members and carers:

- Empathy
- Empowerment
- Acceptance
- Positivity
- Hope

Key terminology

Among family members and carers, terminology can be more informal and casual as they've established a close personal relationship with the YOPD patient. The term 'Parkies' can be used as an endearing term, which most patients won't find as slanderous, or making light of the serious opposition that patients endure. The terms 'Parkies' may even remind some YOPD patients that they belong to a community of young, amazing people who come together to encourage each other. Other charming nicknames used in the YOPD community are 'Parkinson's Peeps' and 'Parkie D's'. It's important to note that before such terms can be used, a good relationship must be established between the patient and family member/carer, and that the patient is not offended by the use of any of these terms.

“Parkinson’s will never stop for a break; you must never give in or give up. If this disorder keeps going, you must keep going even stronger. Stay focussed, persistent and determined.”

Frank C Church

Key audience 3: Communication with people with YOPD (aged under 26 and over 26 years old)

Aims

Aged under 26 years: YOPD patients under the age of 26 years are likely to still be in education or at the very beginning of their career, and YOPD can pose a daunting challenge to anyone looking to go into higher education and build a successful career. A key communication aim is to educate patients under the age of 26 on YOPD so that they fully understand the disease. This will allow them to make the most of any opportunities they may have despite their illness.

Aged over 26 years: YOPD patients over the age of 26 years are likely to be progressing in their careers and either looking to start a family or maintaining one. A diagnosis of YOPD at this age is likely to be extremely scary, as patients will fear that they must sacrifice their career or worry about how they will provide for their family. It will be important to support these patients and empower them to feel like they can have a career and a family whilst managing their disease.

Identifying audience

A diagnosis of YOPD can be very difficult for many patients to come to grips with, and we often find that they will hide this from their family and friends. This can make it difficult to identify patients and offer them the support they need:

- **Diagnosis** – It is important to attract patients to Spotlight YOPD as soon as they are diagnosed, so that they know that they have that support. This can be achieved through leaflets and other patient materials that are given out at the diagnosis stage, directing patients to Spotlight YOPD
- **Social media** – Social media has become a part of most people's everyday routine, and we are seeing more and more support pages being created. Dedicated YOPD support pages on each of the main social media sites would allow those who are still not ready to 'come out' receive support on their own terms.

Audience background

Under 26 years: Patients under the age of 26 years are still developing and still learning. A big motivation for this age group is achieving independence: this can range from going to school on your own to moving out to go to university.

Over 26 years: Patients over the age of 26 years tend to have been working for 5+ years and will have aspirations of progressing in their job or perhaps starting a family.

Key platforms

We are firmly in the digital era, with most of what we interact with being through a digital medium whether that be talking to your friends on WhatsApp, keeping up with the latest trends on TikTok or following your friends and families lives through Instagram or Facebook. It has never been easier to reach a global

audience. With the recent spike in popularity of mental health pages, people are more interested in using social media as a medium to help them better their lives, as such YOPD pages that offered support and advice would be greatly received.

Since the beginning of the COVID-19 pandemic there has been an increasing need for social sharing platforms, and we have seen many disease dedicated forums be created to allow people to interact, share advice with one another and ask questions of each other. These have proven to be very successful, with many patients more confident receiving advice from a fellow patient than from a HCP. Digital connectivity is the best way for people with YOPD to connect with each other and ensure they are supported in their community

Tone and messaging

Under 26 years: Communication with patients under the age of 26 years should be as clear and uncomplicated as possible, particularly for those that are still in school, as they may not fully grasp the extent of their disease and we should be seeking to fully educate them.

- Simple
- Optimistic
- Educational
- Independence

Over 26 years: Patients over the age of 26 years are likely going through the tough time of adjusting their life to their YOPD diagnosis, so therefore it is important to show understanding, and display positive messaging to help support these patients.

- Understanding
- Positivity
- Supportive

Key terminology

When talking to patients with YOPD, it is imperative that you establish what their boundaries are. For example, many patients with YOPD are more than happy to be referred to as a 'Parkie'; however, to some patients this may come across as insulting and offensive. YOPDer is a well recognised term around the community and may be a better alternative until you are familiar with an individual's preference. Other terms include:

- Dysko – Dyskinesia (uncontrollable muscle movement)
- Dystonia – Distortion of the feet and hands
- "on" and "off" states of disease
 - The state of optimism medication, is when the drugs are working as they should and addressing the symptoms is called the "on" state
 - When the medicine isn't working this is called the "off" state

Key audience 4: Communication with HCPs

Aims

- **Increase emotional understanding:** HCPs need a deeper appreciation of the emotional nature of the YOPD diagnosis experience. One of the most important things that HCPs can do after delivering a diagnosis of YOPD is to normalise the difficult and confusing emotions that people recently diagnosed with YOPD are likely to experience. A key aim for HCP communications should be to encourage and drive patients to visit positive resources and information about YOPD
- **Empower HCPs to proactively support with the treatment pathway:** People with YOPD often seek access health advice from the Internet although HCPs are still the core 'gatekeeper' of information. People with YOPD expect guidance from HCPs on what to do and where to go for appropriate health information, and neglecting to provide this guidance will often leave patients without the proper understand of YOPD or where to go to find help
- **Education on research & clinical trials:** HCPs need to be able to understand the latest YOPD clinical data to ensure they are providing the best possible advice for patients
- **Drive pressure on healthcare systems:** To raise the profile of YOPD

Identifying audience

There are a huge number of types of HCPs and sometimes it can be difficult to differentiate between them. Some key audiences that the YOPD community may have touch points with are listed below, with their roles explained.

- **General practitioners:** Otherwise known as GPs, general practitioners are medical doctors who treat common medical conditions and may refer patients to hospitals and other medical services for more specialist treatment
- **Nurses:** Usually work as part of a multidisciplinary team but are often the main point of contact for patients. They often care for a variety of health conditions, but sometimes specialise in particular disciplines
- **Geriatricians:** Are doctors who specialise in the health and care of older people. Due to the link between typical PD and age, many geriatricians have a lot of experience working with patients who have PD. For this reason, some YOPD patients may also be treated by geriatricians at some point in their treatment journey!
- **Neurologists:** Are specialists who are trained in conditions of the nervous system. The neurologist is usually the HCP who will diagnose YOPD, review signs and symptoms, and perform neurological and physical examinations. Although they are experts in neurology, not all neurologists will have come across a YOPD patient in their career!

Audience background

HCPs enter their professions for a number of reasons, but the core of their practice is often centred around patient care. Therefore, many HCPs are motivated by providing positive outcomes for their patients and this is something that can be used to help galvanise change in YOPD awareness, diagnosis and treatment. Despite being caring and empathetic individuals, some subsets of HCPs are heavily

driven by science. Therefore, impactful communication with this audience should marry descriptions of patient outcomes/experience with hard scientific evidence.

Tone and messaging

HCPs are often very dedicated to their careers and their patients. Whilst talking to them about YOPD it is important to be educational, but without undermining their experience and knowledge base. It is often helpful to highlight the significance of the HCP role in patient care, ensuring that their efforts are recognised and validated.

Overall, the tone should be educational, professional and confident. The level of complexity/scientific language that should be used will often depend on the type of HCP that you are communicating with. PD specialists will have a deeper understanding of the disease area than generalists, and it's important to take this into account, such that the specialist does not feel patronised and the generalist does not feel out-of-depth. The level of YOPD awareness amongst HCPs is also likely to vary heavily depending on their level of specialisation and personal experiences. Overarching tactics that are not directed at specific individuals should be accessible to HCPs across the entire spectrum of awareness. However, when a specific individual/HCP sub-audience is being targeted, it might be helpful to assess the extent of their existing awareness and tailor accordingly.

Key terminology

- With HCPs, it is usually okay to use abbreviations (i.e. YOPD), as long as these abbreviations are defined in their first mention
- Scientifically accurate language is essential when communicating with HCPs, but for generalists some of the more complex scientific ideas might require brief explanation
- Suggest not using casual or colloquial terms, such as 'Parkies'. Keep it professional!

Advice for HCPs, from a Matt Eagles, a patient who was diagnosed with YOPD at 7 years old:

“Where possible and more importantly when you feel it is safe to do so try and let the patients be as autonomous as possible. I realise it’s a tough ask but sometimes intervention or voicing concern too vociferously or too early can be distracting for the patient and interrupt their concentration and actually cause them to fall.

Be patient, be kind and be prepared to share some of your own stories. Communication isn’t and shouldn’t be just one way. It builds relationships, which in turn builds confidence and trust which enables you to make decisions together.”

HCPs are a key contact point for all YOPD patients and so the HCP attitude and behaviour is critical for patient experience.

Key audience 5: Communication with policymakers and corporate sponsors

Aims

Rare diseases can be forgotten about by sponsors and the government alike. However, they hold the financial and political power for mobilising funding and research into YOPD. Ultimately, all five aims of Spotlight YOPD need donors and policymakers to drive the changes needed to support people with YOPD.

- **Guidelines and resource provision:** Improving resources and guidelines available for patients by adding YOPD to NICE and NHS England guidelines
- **Recognition of YOPD as a rare disease for improved support:** Government backing of initiatives to mobilise support such as carer allowance, parking schemes and recognition of YOPD in the workplace
- **Increased funding into research and support for YOPD:** Greater corporate funding into genetic testing, YOPD research and treatment options will all support the outcomes for people with YOPD

Audience background

Policymakers such as NICE, NHS England and the Care Quality Commission and associated bodies create the guidelines and resources for YOPD patients.

Government: Governments have power to release grants, loans and financial support. Associations such as NHS, NICE Scottish Medicines Consortium (SMC) and the National Centre for Pharmacoeconomic Evaluations (NCPE) can also decide which treatments get funding. Many decisions that we need to drive change are up to the politicians and local councillors/MPs.

Corporate sponsors: Key to funding decisions and driving research. Include pharmaceutical companies and large patient organisations.

Key platforms

This audience is best reached using email campaigns, formal applications and written recommendations. Directly reaching out to relevant individual bodies directly is likely to gain the best response. Working with a large patient support organisation such as Parkinson's UK or European Parkinson's Disease Association (EPDA) can support the conversation when reaching out to these audiences. As aforementioned, social media is a powerful tool for campaigning and lobbying. Twitter is a platform that could be mobilised to create a campaign and spread the message.

Reaching out to politicians can also be achieved using the following channels:

- Quarterly policy briefings on specific YOPD and community support policy areas
- Look into creating an All Party Parliamentary Group
- Ensure all press releases are sent to relevant government department in advance
- Utilise positive media and stories

Tone and messaging

The tone for reaching out to government bodies and corporate sponsors must be professional yet persistent. We need to approach local MPs and councillors with a clear description of what we want to see changed in policy and use strong evidence base. It is important to demonstrate good knowledge of the current YOPD policy environment, use robust evidence and demonstrate with our communications that we are a well-respected, authoritative organisation.

The messaging for corporate sponsors needs to highlight that they have the ability to make change if they help us. They can support campaigns by writing to their MP, signing e-petitions, donating to Spotlight YOPD and boost the profile of any campaign.

Finally, YOPD is lesser known among policymakers than the YOPD community so it is important to ensure this target audience has a clear understanding of what YOPD is, to help inform their decision making. Working with the pharmaceutical industry and associated communications companies can allow the development of educational resources and important materials to support the evidence base for why YOPD should be included in national guidelines.

Summary and close

This communications strategy shows how effective communications can:

- Help achieve our overall aims and vision
- Engage effectively with stakeholders
- Ensure people understand YOPD and patients feel supported
- Position Spotlight YOPD as a reliable resource for information and support
- Change behaviour and perceptions towards YOPD

By utilising the suggested communications tactics, targeting the correct audience, and using the recommended platforms, we hope Spotlight YOPD can achieve its aims and supports YOPD patients for a brighter future.