

# A **holistic** approach to **patient care** in **pulmonary arterial hypertension**

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A report developed by Actelion Pharmaceuticals Ltd in  
consultation with an international expert steering group

# Contents

Executive summary	3
International steering group	4
Foreword	5
PAH management today: where are we now?	6
A closer look at patient information needs	10
Understanding challenges in patient communication	11
<i>Case study 1</i>	13
Recommendations for holistic PAH care	14
<i>Case study 2</i>	15
Mapping the optimal patient journey	16
Conclusion	17
References	18
Disclosures	19

# Executive summary

Over the past 20 years, Pulmonary Arterial Hypertension (PAH) has transitioned from being a fatal disease with a poor prognosis to a long-term condition that, with the right treatment and support, can be managed.

Advances in knowledge and treatments mean that many people with PAH today are living longer and leading more active lifestyles than they were a decade ago. In addition, patients can expect to receive specialist care from highly experienced, dedicated multidisciplinary healthcare teams. These developments, while positive, bring new challenges which extend beyond treating the physical symptoms and delaying the progression of the disease.

In April 2015, Actelion organized a meeting of international experts in PAH, to discuss how patient care could be improved to address the wider needs of patients. The group, which included specialist PH physicians, nurses and representatives from patient associations (see page 4 for full list of members), examined the current roles of the multidisciplinary healthcare team and patient associations, and explored the information and communication needs of all stakeholders involved in the care pathway. The group identified a number of opportunities or ‘gaps’ in information and communication that could be addressed to improve the holistic care of patients. This report summarizes key insights from the group’s discussions, referencing these to the available literature, and presents a number of recommendations for action put forward by the group during and after the meeting.

Where possible, the literature referenced in this report focusses on PAH patients specifically; however, where relevant, insights have also been drawn from literature on patients with pulmonary hypertension as well as other long-term conditions. In addition, potential recommendations for action have been drawn from models of care used in non-PAH settings, among patients with other long-term conditions such as heart disease and cancer.

This document is aimed at all healthcare team members involved in PAH patient care, as well as PAH patient associations, and is intended to form a platform for further discussion on how PAH patient care may be improved. The recommendations put forward here may also be used as interim guidance for a best practice, multidisciplinary approach to holistic PAH patient care.

Actelion is committed to supporting the PAH community and dedicated to improving PAH patient care. Both the international multidisciplinary group meeting and this report were initiated and funded by Actelion Pharmaceuticals Ltd. as part of this commitment to support patients in living with PAH as ‘a part of their life’.

## The recommendations for action contained in this report are as follows:

1. In line with current ESC/ERS Guidelines,<sup>1</sup> PAH care should be delivered by a specialist, multidisciplinary team with access to broader expertise and support as needed to manage the wider impact of PAH, including the support of PAH patient associations.
2. Close links and effective communication between PAH patient associations and the multidisciplinary healthcare team will help ensure that all team members understand the services and support available through patient associations, and can draw upon these resources to make appropriate referrals to patients as necessary.
3. Patient engagement should be integrated into PAH care delivery as standard from the point of diagnosis; multidisciplinary healthcare team members should receive training on how to better engage patients to participate in their own care, including communication skills, making shared decisions and understanding patient information needs.
4. High quality information, both written and verbal and tailored to the individual needs of the patient, should be delivered to the patient at regular intervals, allowing the patient to accumulate knowledge and skills in the months following diagnosis and to become empowered to live well with PAH.

# International steering group

## PAH specialist physicians

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This report was developed by Actelion’s Global Advocacy function in collaboration with the International Steering Group.

# Foreword

The outlook for patients with Pulmonary Arterial Hypertension (PAH) has undergone significant change in the past few decades. There are now many treatments available for the disease, along with specialized care delivered by a multidisciplinary healthcare team, leading to improvements for patients in terms of managing their symptoms and disease progression.

As in other disease areas that have undergone a similar transition, this development has led to a shift in terms of what patients with PAH need. The range of treatment options now available means patients need more information about these choices, so that they can work with their healthcare team to make treatment decisions that are right for them. With patients experiencing a better quality of life and slower disease progression, patients need care that goes beyond their physical symptoms and addresses the impact of the disease on many aspects of their lives, such as emotional and social wellbeing, family life and work.

To meet the evolving needs of PAH patients who are now living with a long-term condition, a more holistic approach to their care is required – one that recognizes the importance of supporting patients to participate in their own care. ‘Activated’ patients seek out information, make shared decisions with their healthcare team and take action in relation to self-management.

In order to engage patients to participate in their own care and become effective ‘self-managers’, two components are essential: 1) information and 2) effective communication. High quality information, delivered to patients in the right way and at the right time – about the disease, how it can be treated and managed, how to live well with it and where to go for support – can be a real game-changer and should be regarded as a therapy in its own right. Likewise, effective communication, including motivational interviewing and care planning between the multidisciplinary healthcare team, patient associations and patients, can empower patients. This empowerment enables patients to take a more active role in decisions about their care and improve their own self-care, which has the potential to lead to better patient outcomes.

As a patient with a long-term condition myself and as the founder of the Patient Information Forum (PIF) in the UK, I am passionate about effective patient communication. For me, the impact of information should not be underestimated and it needs to be integrated into healthcare delivery. I was delighted to facilitate the international multidisciplinary group workshop in April 2015 and would like to extend my thanks to all members of the steering committee for participating in the discussions and in coming together to develop this report.

Mark Duman – healthcare professional and founder of the Patient Information Forum [www.pifonline.org.uk](http://www.pifonline.org.uk)



# PAH management today: where are we now?

## 1. Recent advances in understanding and treating PAH have improved the outlook for PAH patients.

The outlook for PAH patients has changed significantly in recent decades.<sup>2</sup> Until the mid-1980s, PAH was associated with a poor prognosis<sup>3</sup> as effective therapies were not available.<sup>2</sup> However, improvements in our understanding of the disease<sup>4</sup> and the availability of effective treatments<sup>5</sup> mean that people with PAH today can expect to live longer<sup>2</sup> and lead more active lifestyles.<sup>6</sup> In addition, patient care delivered via specialist, multidisciplinary healthcare teams now has a greater focus on quality of life considerations alongside the clinical symptoms of the disease.<sup>2</sup>

“In my experience, the most important steps in PAH management over the last few years have been coordinating care, the development of multidisciplinary teams and setting international guidelines that people can follow.

Wendy Gin-Sing, PAH specialist nurse, Hammersmith Hospital, London, UK

PH is becoming a much more treatable disease, much more like diabetes. If we think of it in those terms, we can really understand what kind of progress we’ve made over the last decade to reach a point where people are able to live with PH as a manageable condition.

Rino Aldrighetti, President of the Pulmonary Hypertension Association, US

## 2. PAH patients require support that goes beyond the physical symptoms of the disease.

PAH patients need support that takes into consideration broader needs, ‘beyond simple physiological measurements’.<sup>6</sup> The first large scale survey to explore the perspective of PAH patients in Europe<sup>7</sup> highlighted that for 85% of patients, employment, work and income are all affected by their disease. Results also highlighted the emotional impact of PAH; 35% of patients report feelings of frustration, anger and low self-esteem. More than half feel isolated and many state that their relationships are severely affected. Another study revealed that 20–40% of patients experience anxiety and 21–55% experience depression.<sup>4</sup>



The impact of pulmonary arterial hypertension (PAH) on the lives of patients and carers: results from an international survey. 2012

PAH can cause feelings of:

Frustration Anger Worthlessness  
Feeling misunderstood  
Low self-esteem Isolation

In line with these findings, Guidelines published by the European Society of Cardiology (ESC) and the European Respiratory Society (ERS) state that

‘pulmonary hypertension is a disease with a significant impact on the psychological, social (including financial), emotional and spiritual functioning of patients and their families’; accordingly,

‘teams managing these patients should have the skills and expertise to assess and manage issues in all of these domains’.<sup>1</sup>

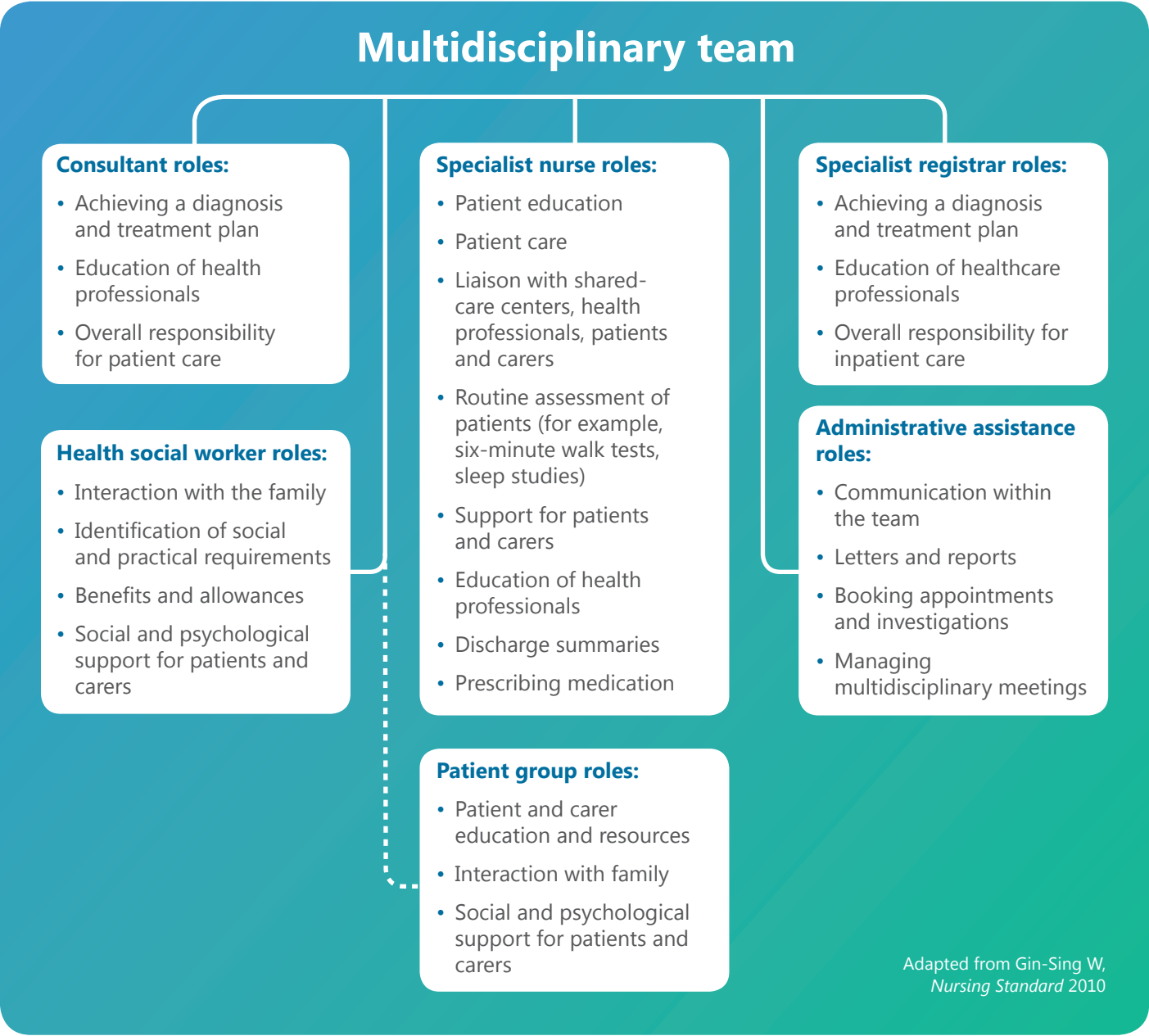
## 3. PAH care requires a specialist, multidisciplinary team approach, including the support of patient associations.

Effective management of PAH requires a multidisciplinary approach involving healthcare professionals and other team members from various different specialties<sup>2</sup> as well as patient associations,<sup>1</sup> which can play a key role in meeting the wider needs of patients.

While PAH care varies between countries in terms of how it is structured, ESC/ERS and CHEST Guidelines recommend that care is delivered via a specialist pulmonary hypertension referral center<sup>5</sup> involving the following parties:<sup>1,2</sup>

- A consultant physician (cardiology and/or respiratory specialist) experienced in pulmonary hypertension, who can prescribe therapies that target the disease
- A specialist nurse who can educate the patient on how to manage their symptoms and treatment and provide day-to-day support
- Medical professionals with relevant expertise in pulmonary hypertension diagnostic testing, for example radiologists and cardiologists
- National and/or European pulmonary hypertension patient associations which can provide information and support, particularly in relation to patients’ wider needs beyond physical symptoms
- Social workers who can support the patient in terms of managing their life at home, for example in relation to finances or practical arrangements
- Access to a network of colleagues in other relevant disciplines, such as psychiatry, clinical psychology or welfare

Local healthcare professionals and general nurses can also provide support and coordinate with the multidisciplinary team members above.<sup>5</sup>



4. Effective communication between all members of the multidisciplinary team, including between healthcare professionals and patient associations, is crucial for optimal care.

Effective communication between all members of the multidisciplinary team is a necessity for optimal PAH care. All team members should be aware of each individual patient’s general needs and confer or cross-cover roles

5. PAH patients need to be better informed.

Studies have consistently suggested that patients want more information than they currently receive.<sup>8</sup> One study found that more than 20% of patients with chronic diseases were not aware of the different medical treatments available for their condition.<sup>8</sup> Another survey among PAH patients found that many feel they are given too little information by their healthcare professionals, particularly on topics such as treatment (67%), the disease itself (61%) and the healthcare professionals that are involved in PAH care (47%).<sup>7</sup> Over one third want more information on the emotional impact of the disease, and 34% want more information on the financial consequences.<sup>7</sup>

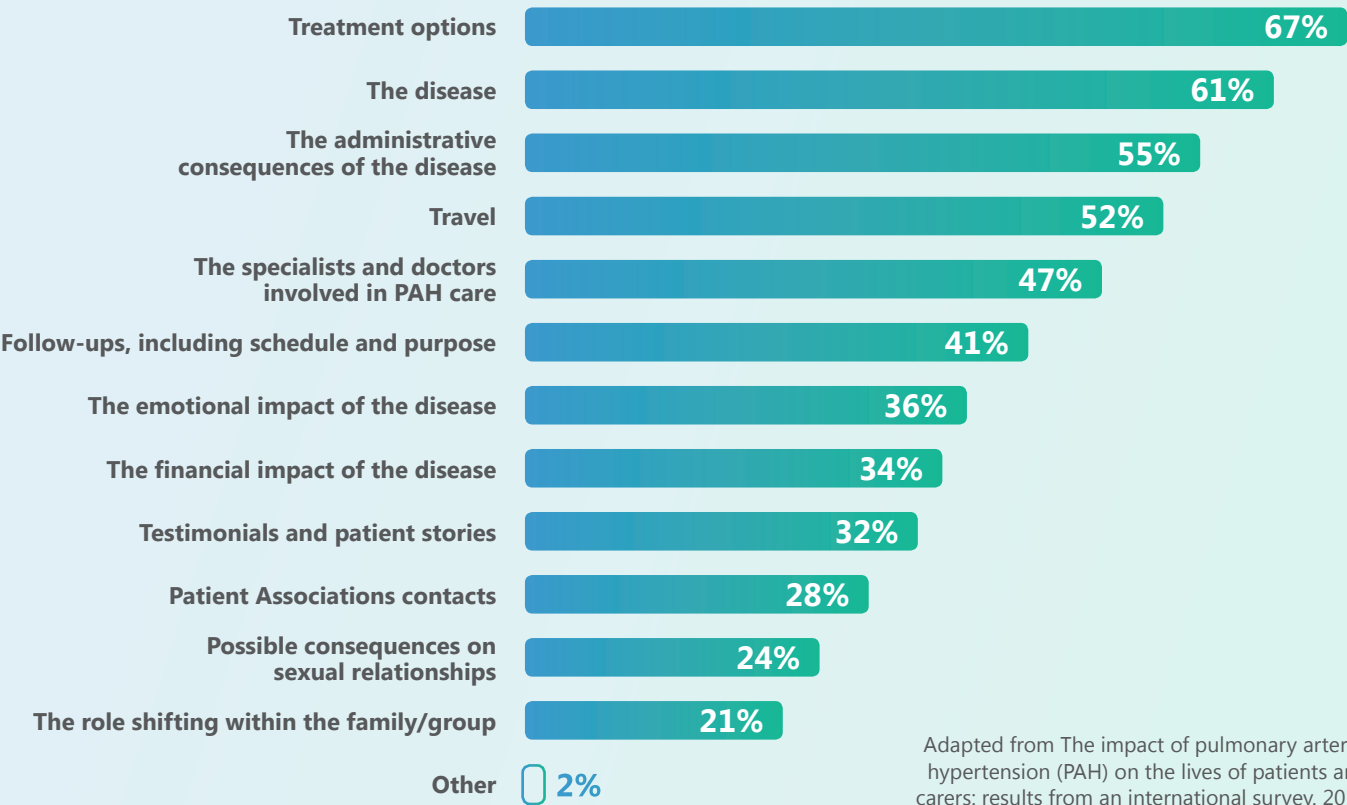
as appropriate and within the boundaries of patient confidentiality.<sup>2</sup>

In particular, close links and effective communication between PAH patient associations and the multidisciplinary healthcare team members will help ensure understanding of the services and support available through patient associations, so that healthcare professionals can make appropriate referrals to their patients as necessary. Evidence suggests that the support and services available via patient associations could be better understood, especially among healthcare professionals.<sup>4,8</sup>

The link between access to information and successful PAH management is well established.<sup>2</sup> For example, healthcare professionals report that patients who receive comprehensive guidance at the beginning of treatment have better outcomes;<sup>2</sup> the same is true of patients who have access to their own medical records.<sup>9</sup> Information is understood to motivate patients to participate in their own care, thereby improving outcomes.<sup>10</sup>

The importance of informed carers and family members should not be overlooked here. Survey findings have shown that carers are likely to be more proactive than patients in sourcing information and as they are heavily involved in attending patient appointments and supporting with the patient’s everyday needs, healthcare professionals should also take care to address their information needs.<sup>7</sup>

PAH patients surveyed wanted information about...



Adapted from The impact of pulmonary arterial hypertension (PAH) on the lives of patients and carers: results from an international survey. 2012

6. Patient engagement and self-management should be key considerations in PAH care.

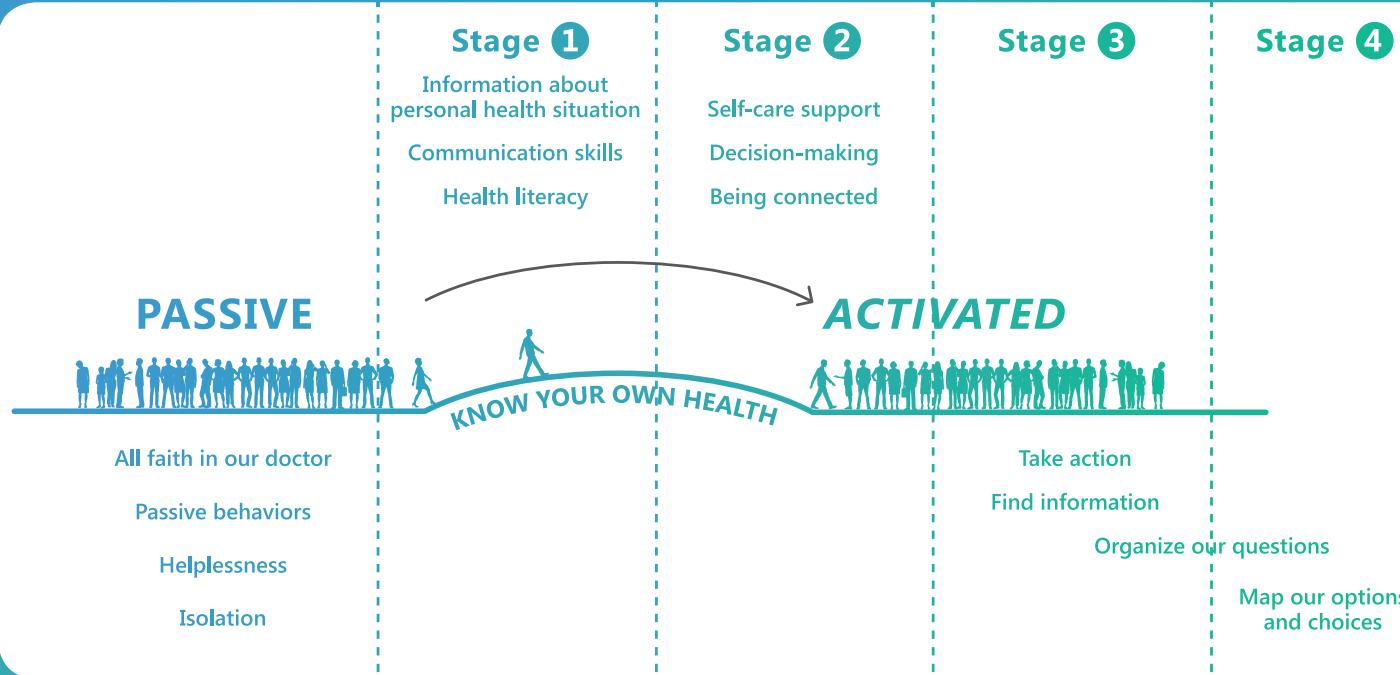
Within a traditional healthcare delivery model, the patient is a passive recipient of medical care; however, there is an ‘emerging consensus’ that patients can and should be actively involved in their own care, particularly patients with chronic conditions<sup>8</sup> like PAH whose burdens extend beyond physical symptoms. Patients can be involved in their care by, for example, their healthcare professional initiating a discussion regarding what to expect from treatment or how to manage complications.<sup>11</sup>

‘Activated’ patients – those that engage in their own care by seeking out information and knowledge, expressing preferences and collaborating with their healthcare team to make shared decisions, and taking action in relation to

self-care – have been shown to experience better health outcomes at a lower healthcare cost.<sup>12</sup> Other benefits of patient activation include increased patient satisfaction, enhanced confidence and reduced anxiety.<sup>8</sup>

Developed by Judith Hibbard and colleagues at the University of Oregon, the ‘Patient Activation Measure’ (PAM) scoring system describes four stages of patient activation.<sup>13</sup> According to Hibbard, patients must sequentially pass through each of the four stages for optimal results:<sup>8,13</sup>

**Stage 1:** Believing the patient role is important;  
**Stage 2:** Having the confidence and knowledge necessary to take action;  
**Stage 3:** Taking action to maintain and improve one’s health;  
**Stage 4:** Staying the course, even under stress.



PAH management today: where are we now?

Summary of key insights

- Recent advances in understanding and treating PAH have improved the outlook for PAH patients
- PAH patients require support that goes beyond the physical symptoms of the disease
- PAH care requires a specialist, multidisciplinary team approach, with patient associations playing a key role
- Effective communication between all members of the multidisciplinary team, including between healthcare professionals and patient associations, is crucial for optimal care
- PAH patients need to be better informed
- Patient engagement and self-management should be key considerations in PAH care



# A closer look at patient information needs

## 1. Information needs to be of high quality and relevant to the individual patient.

While many patients with PAH identify a need for ‘more’ information,<sup>7</sup> the quality of that information is a key factor in determining its impact.<sup>14</sup> Research has shown ‘significant shortcomings in much of the information that is available to patients, including inaccurate and misleading statements; omission of topics of relevance to patients; and inadequate or incomplete information about treatment options, risks and side-effects’; hence patients want ‘better information’ about the disease, treatments and lifestyle issues.<sup>8,10</sup>

Information should also be relevant to a patient’s individual needs and preferences, which will vary

according to factors such as age, educational status and cultural background.<sup>10</sup> This points to the role of the multidisciplinary healthcare team, including patient associations, in directing patients (as well as their carers or family members) to information that is appropriate to them as individuals.

For younger children of parents with PAH, the impact of the disease can be hard to understand and some tailored resources have been developed to support parents in explaining their condition to their children. For example, specialists at Imperial College Healthcare NHS Trust in London partnered with Medikidz, a company specialising in the creation of unique comic books to help children understand complex diseases, to develop *Medikidz Explain Pulmonary Arterial Hypertension (PAH)*. This is available to parents through the patient association in the UK.

## 2. When and how information is delivered to patients are key considerations.

In order to have maximum impact, high quality information that is relevant to the individual patient needs to be delivered in the right way and at the right time, reflecting their changing needs over the course of the care pathway.

Around the time of diagnosis, most PAH patients would like more information on the disease, treatment and the multidisciplinary team members who will be delivering their care.<sup>7</sup> However, information provided verbally at the point of diagnosis can be forgotten due to shock,<sup>7</sup> indicating the potential value of offering written materials to the patient when they decide they are ready and able to digest them. For example, survey results show information on the emotional and practical impact of PAH patients’ disease would be welcomed by patients about a month after diagnosis.<sup>7</sup>

Studies among patients with other chronic diseases such as cancer similarly highlight the way in which patients’

information needs change over time.<sup>15,16</sup> For example, at diagnosis, individuals rank information about treatment as most important, while after a few months, they want information about the effect of treatment on their family.<sup>15</sup>

It is important to remember that a patient may see their local or family doctor at more regular touchpoints throughout the year than their specialist PAH team. It is therefore important that non-specialists interacting with patients are appropriately educated about the disease and its day to day management from their specialist peers, to best support the individual.

The preferred source of information among patients with chronic conditions is their doctor (73%), followed by the internet (30%), then nurses (22%)<sup>8</sup> underscoring the importance of healthcare professionals being aware of key sources of high quality information, such as those available from patient associations. Only 5% of patients surveyed with chronic conditions mention patient associations as a source of information,<sup>8</sup> indicating the lack of awareness of the support and services provided by patient associations that has already been mentioned.

# A closer look at patient information needs

## Summary of key insights

- Information needs to be of high quality and relevant to the individual patient
- When and how information is delivered to patients are key considerations

# Understanding challenges in patient communication

## 1. It is important for healthcare professionals to use language that is easy for the patient to understand.

Communication between healthcare professionals and patients would be enhanced by healthcare professionals using ‘clear and simple’ language that is easy for patients to understand.<sup>17</sup> One study found that around 17% of patients do not feel that their healthcare professional clearly explains details regarding tests and treatments<sup>10</sup> and another found that only 9% of patients would ask for further clarification if they did not understand something their doctor had said.<sup>8</sup>

“When I see a patient I may see them for 15 minutes, half an hour, maybe even an hour – but even that hour in 365 days of the year is just a fraction of a per cent of their time. Sometimes it’s very easy I think, for the patient to put on a brave face at that moment and we don’t really scrape the surface.”

Dr Luke Howard, PAH specialist, Hammersmith Hospital, London, UK

“If a patient is educated or understands the disease then they ask the physician the right question; and if they ask the right question, the physician is forced to explain it better and in some cases, helps them pay more attention to the patient.”

Dr Zeenat Safdar, PAH specialist, Baylor College of Medicine, Houston, US

## 2. The benefits of patient engagement and self-management need to be more fully understood.

The benefits of patient engagement and self-management could be better understood by stakeholders involved in PAH care, including healthcare professionals. Research indicates that patients do not routinely receive encouragement for self-care from their healthcare professionals; 55% of patients with chronic

diseases report that they do not often receive such encouragement, and 33% say they have never done so.<sup>8</sup>

While healthcare professionals need to be aware of the benefits of encouraging patients to be engaged participants in their care, it is also important for patients to understand the importance of taking an active role. According to Judith Hibbard’s four-stage activation process (page 9), patients must first recognize the importance of their role before they can go on to acquire the skills in order to actively self-manage.<sup>13</sup>

### 3. Healthcare professionals need more training on how to engage patients and make shared decisions.

Research shows that many patients want to be involved in decisions about their care.<sup>10</sup> However, differences between the expectations and priorities of both the healthcare professional and the patient<sup>6</sup> can negatively impact shared decision-making. One study found that 24% of patients do not feel involved in decisions regarding their care by their healthcare professional,<sup>10</sup> and another highlighted that 20% of patients with

chronic diseases are not aware of the different medical treatments available for their condition, suggesting that they were not involved in the decision about how to treat their condition.<sup>8</sup>

Healthcare professionals may need training in the skills required to support patient engagement and shared decision-making.<sup>10</sup> Certain populations, such as the elderly or less educated, will need more intensive support to become active participants in their own healthcare. All patients will need individualized support and guidance,<sup>10</sup> so it is important that healthcare professionals receive appropriate training to ensure that they can provide this.

### 4. There is low awareness of the support and services available via patient associations.

National and European-level patient associations offer a wide variety of services and support to PAH patients and their families (see case study opposite), but stakeholders involved in PAH care are not always aware of these. This is underscored by widespread feedback received by the patient association steering committee members, and supported by a study which highlighted that only 30% of patients with chronic diseases are aware of relevant associations.<sup>8,10</sup> Clearly, more needs to be done to connect patients to their local associations; furthermore, 'given that most patients look to their doctors first and foremost for information about their health, it suggests that building awareness among doctors and other health professionals about patient associations should be a priority'.<sup>8</sup>

## Case study 1:

### Strategies adopted by the Pulmonary Hypertension Association

Established in 1991, the Pulmonary Hypertension Association (PHA) is the largest and longest-running PH association in the world, supporting more than 16,000 members.

#### Delivering information to the patient

PHA develops diverse and engaging information resources which aim to empower patients to connect with each other and learn about PH and its management. It aims to offer a personalized approach to information delivery through, for example, the myPHA online tool, which surveys the user and offers personal recommendations to resources, helping them access information that is relevant to them as individuals.



#### Supporting a multidisciplinary approach

To facilitate effective communication between the association and the medical teams that manage the patient's healthcare, PHA has an established Scientific Leadership Council. The council is comprised of 28 global leaders in the field of PH, including specialist clinicians and researchers. It provides medical and scientific leadership and guidance for PHA, supports the development of educational resources for medical and public audiences

and advocates to raise awareness about pulmonary hypertension. Two medical membership structures, PH Clinicians and Researchers (over 700 members) and PH Professional Network (over 1,200 nurses, pharmacists, respiratory therapists and other non-MD medical professionals) accelerate this support.

#### Other services provided by PHA include:

- Local support groups and telephone support lines
- National, regional and international educational programs delivered via face to face meetings or online training
- Research grants to fund rising leaders in the field of PH
- Professional networks for physicians and non-physicians, to support knowledge and ideas sharing
- Awareness raising initiatives, such as celebrating World PH Day (5 May) and campaigning for early diagnosis
- Fundraising events
- Political lobbying for better care
- Patient/carer discussion boards and online chat forums
- Multiple platforms to reach newly diagnosed and other unconnected patients.

To find out more, visit [www.phassociation.org](http://www.phassociation.org).

## Understanding challenges in patient communication

### Summary of key insights

- It is important for healthcare professionals to use language that is easy for the patient to understand
- The benefits of patient engagement and self-management need to be more fully understood
- Healthcare professionals need more training on how to engage patients and make shared decisions
- There is low awareness of the support and services available via patient associations



# Recommendations for holistic PAH care

**The following recommendations are proposed for implementing a holistic approach to PAH care:**

- In line with current ESC/ERS Guidelines,<sup>1</sup> PAH care should be delivered by a specialist, multidisciplinary team with access to broader expertise and support as needed to manage the wider impact of PAH, including the support of PAH patient associations.
- Close links and effective communication between PAH patient associations and the multidisciplinary healthcare team will help ensure that all team members understand the services and support available through patient associations, and can draw upon these resources to make appropriate referrals to patients as necessary.
- Patient engagement should be integrated into PAH care delivery as standard from the point of diagnosis; multidisciplinary healthcare team members should receive training on how to better engage patients to participate in their own care, including communication skills, making shared decisions and understanding patient information needs.
- High quality information, both written and verbal and tailored to the individual needs of the patient, should be delivered to the patient at regular intervals, allowing the patient to accumulate knowledge and skills in the months following diagnosis and to become empowered to live well with PAH.

To help fulfil these recommendations, engage patients to participate in their own care and support a holistic approach, the following potential practical solutions have been identified.

**1. Training for healthcare professionals and other multidisciplinary team members**

Training for those responsible for delivering PAH care, particularly healthcare professionals, may be beneficial across a number of areas. Areas for training include: the benefits of patient engagement and self-management; how to work collaboratively with patients to motivate them to participate in their own care; communicating with patients using language that is easy for them to understand; managing the broader aspects of PAH beyond the physical symptoms; and understanding the support and services available from patient associations. Such training may be delivered to healthcare professionals by their own hospitals or medical institutions, though it is important to recognize the insights and resources that patient group

representatives can provide to healthcare professionals to support more effective communication with patients.

**2. ‘Information prescriptions’**

To integrate high quality information into the healthcare pathway in a way that is tailored to the needs of the individual, the idea of an ‘information prescription’ has been put forward. In the same way that a healthcare professional prescribes medicine, information could be selected by the healthcare professional and ‘prescribed’ on the basis of the individual patient’s needs, goals and the stage of their journey. This may include information on PAH and its management including the broader aspects of the disease beyond physical symptoms, as well as referral to a local patient group.

**3. Written care plan**

Developing a written care plan can be beneficial to the patient in a number of ways. For example, it emphasizes the importance of collaboration and shared decision-making between the patient and healthcare professional, and may help the patient understand that there are a variety of options available to them. It encourages the patient to consider their own role in their care. It also provides a record of information about the patient’s care, which they can refer back to between consultations.

**4. Patient ‘passports’**

Taking the ‘information prescription’ concept one step further and building on the idea of patient-accessible electronic records, a digital or hard copy patient ‘passport’ may be very useful for both patient self-management and as a central record to improve information sharing between the multidisciplinary team. This would be held by the patient and contain all the information relevant to their PAH care, such as information on the disease, available treatments and their written care plan; a record of test results; information on self-care and the broader aspects of the disease; and where to go for support. Taking the ‘information prescription’ concept one step further and building on the idea of patient-accessible electronic records, a digital or hard copy patient ‘passport’ may be very useful for both patient self-management and as a central record to improve information sharing between the multidisciplinary team. Some patient groups (e.g. PHA in the US and German PH Association) have examples of such passports to download or order from their websites. A website collating all patient group materials for patients and their families, Our PH Library, is also of use to healthcare professionals to browse existing resources that are available to them, at [www.ourphlibrary.com](http://www.ourphlibrary.com).

**5. Patient self-management tool**

To assist patients in accessing information that is relevant to them and their individual situations, a self-assessment and management tool may be developed.

**6. Self-management courses**

Structured self-management courses could be offered to patients by their multidisciplinary healthcare team, to educate and activate patients early following the diagnosis.<sup>2</sup>

These courses could be modelled on the rehabilitation services currently offered to patients with other chronic diseases, such as heart disease and cancer.<sup>18,19</sup>

**7. Patient mentoring**

As a complement to support accessed through a patient’s multidisciplinary healthcare team and patient associations,

patient-to-patient mentoring may be beneficial in providing patients with individualized support, particularly as regards the broader aspects of PAH beyond physical symptoms. Patients could be matched according to factors such as age and cultural background.

**8. Promoting patient associations**

The lack of awareness of the existing services and support available via patient associations could be addressed by activities to promote their offering. Primarily, training healthcare professionals on the services available is a priority so that healthcare professionals can act as a conduit to these services for patients. Other activities could include training patient association members in marketing skills and activities both via social media and traditional routes, so the associations can enjoy a higher profile and visibility among PAH patients.

## Case study 2:

### Rehabilitation Program for PH in Norway – a holistic rehabilitation approach

Following the advice of the Norwegian PH patient association, the Feiringklinikken heart rehabilitation center near Oslo established a rehabilitation program for PH patients in 2011, inspired by the rehabilitation program at Heidelberg University in Germany [Grünig 2012, Grünig 2011, Becker-Grünig 2013, Nagel 2012]. The program offered for PH patients currently includes supervised exercise training as well as a range of sessions provided by a multidisciplinary team including PH specialist physicians, nutritionists, psychologists, physiotherapists, legal advisors and a patient group representative. This team approach offers a genuinely holistic approach to PH care.

The feedback from its annual intake of 6-8 PH patients is consistently positive; patients feel much more secure understanding what level of exercise is ‘safe’ for them as individuals and they benefit from the positive lifestyle choices they can make to complement their medication regimen and proactively manage their condition. Its success has been further demonstrated by patients and professionals from other countries coming to Norway to take part in or learn from the program.

As more specialist centers adopt a similar rehabilitation program, it is important that they share information and results where possible. This will help to advance research and understanding about PH and exercise, with the ultimate aim of improving the way the condition is managed.

Further information on how the program was established in Norway can be found via the News Archive of the Feiringklinikken website at: <https://www.lhl.no/om-lhl/aktuelt/nyhetsarkiv-2012/2012/nytt-gruppetilbud-ved-feiringklinikken/>.



*PH patients cooking healthy food in the training kitchen*



# Mapping the optimal patient journey

To facilitate holistic PAH care from the point of diagnosis onwards, patients should be encouraged to engage and participate in their care, progressively passing through the four stages of activation.<sup>13</sup> This is facilitated by appropriate access to information and effective communication between stakeholders at each phase of the patient’s journey. While every patient’s journey and needs differ, an example of an optimal journey for holistic care is suggested below, outlining patient information needs and stakeholder roles at each stage, with all stages to be delivered within a timeframe of approximately 6 to 9 months.

	Patient activation stage <i>[Hibbard 2004, p1005]</i>	Patient information	Stakeholder roles
Diagnosis	Stage 1. <i>Believing the patient role is important.</i>	<ul style="list-style-type: none"><li>• Information about the disease, treatment options, specialists involved in PAH care and managing the emotional impact, including support available via patient associations</li><li>• Written materials for patient to take away upon request when they feel ready to digest them</li></ul>	<ul style="list-style-type: none"><li>• Healthcare professional to use patient-friendly language and establish open and equal communication to create context for patient engagement and self-management</li><li>• Healthcare professional to refer patient to patient association for immediate support as desired by the patient</li></ul>
Appointment 1 after diagnosis	Stage 2. <i>Having the confidence and knowledge necessary to take action.</i>	<ul style="list-style-type: none"><li>• Written care plan following shared decision-making with healthcare professional</li><li>• Patient passport with content tailored to individual patient’s needs</li><li>• Further information tailored to individual needs supplied by patient association</li></ul>	<ul style="list-style-type: none"><li>• Healthcare professional to facilitate shared decision-making with the patient</li><li>• Patient association to provide support and information tailored to patient’s individual needs</li></ul>
Appointment 2 after diagnosis	Stage 3. <i>Taking action to maintain and improve one’s health.</i>	<ul style="list-style-type: none"><li>• Referral to disciplines outside core healthcare team as needed e.g. psychiatry, welfare</li><li>• Patient-to-patient mentoring matched according to age/ background etc.</li></ul>	<ul style="list-style-type: none"><li>• Multidisciplinary team to work closely together to identify patient’s needs and refer on to other disciplines as necessary</li><li>• Potential for patient associations to facilitate patient-to-patient mentoring</li></ul>
Appointment 3 after diagnosis	Stage 4. <i>Staying the course, even under stress.</i>	<ul style="list-style-type: none"><li>• Self-management course to support rehabilitation</li><li>• Ongoing engagement with multidisciplinary healthcare team and patient associations to maintain activated behavior in the context of day-to-day life</li></ul>	<ul style="list-style-type: none"><li>• Patient associations and multidisciplinary healthcare team to provide ongoing, coordinated support</li></ul>

# Conclusion

Recent advances in knowledge and treatment have improved the outlook for PAH patients.

The availability of specialized care delivered by a multidisciplinary healthcare team with a greater focus on quality of life considerations has further improved outcomes.<sup>2</sup> While positive, these developments have opened up fresh challenges for patients and created new areas of unmet need, as has been highlighted by recent analyses of the broader impact of PAH and patient perspectives on living with the disease.<sup>3,7</sup>

Within this context, it is clear that a holistic approach to PAH care is needed, driven primarily by the multidisciplinary healthcare team with the involvement of patient associations and facilitated by effective communication between all stakeholders and an optimal flow of information to the patient.

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18 A holistic approach to patient care in pulmonary arterial hypertension

## Disclosures

This report was initiated and funded by Actelion Pharmaceuticals Ltd, as part of its commitment to supporting the PAH community and improving PAH patient care. The report was developed with support from Packer Forbes, a healthcare communications agency.

Steering committee members were paid for their attendance at the multidisciplinary workshop, to provide their advice and experts insights. None of the steering committee members involved were paid for their input into the development of this report.

A holistic approach to patient care in pulmonary arterial hypertension 19



