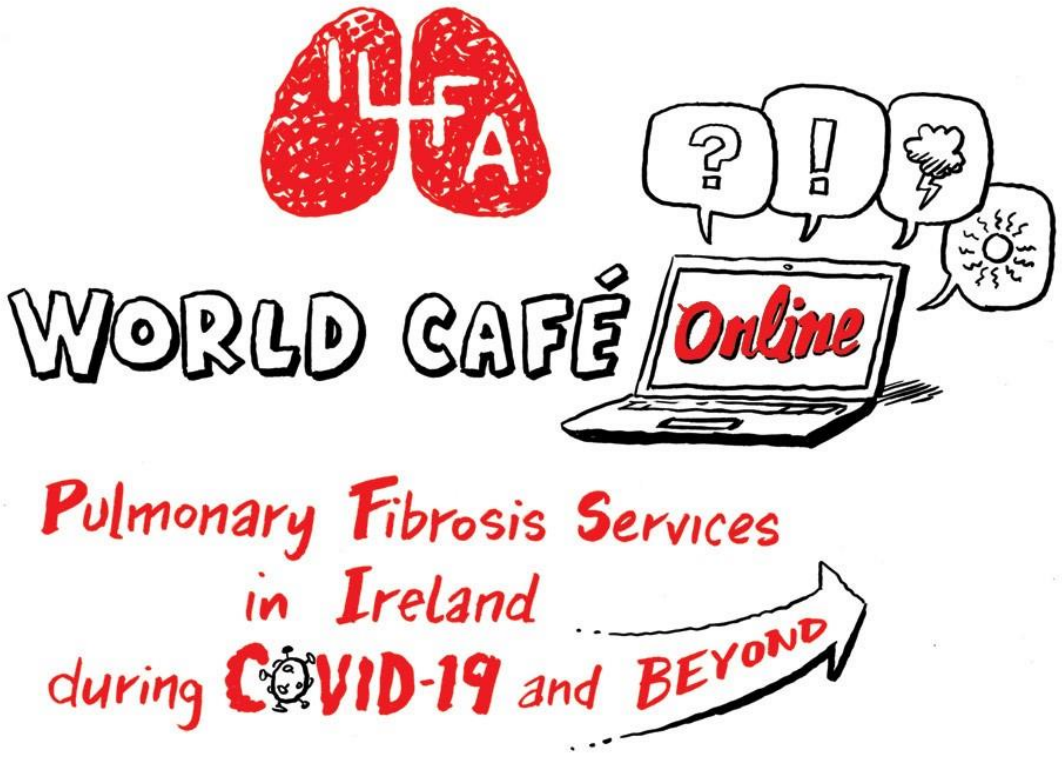

The Urgent Need for a National Clinical Programme for Pulmonary Fibrosis:

Results from the Irish Lung Fibrosis Association Multi-Stakeholder World Café on Pulmonary Fibrosis Services in Ireland During Covid-19 and Beyond

Irish Lung Fibrosis Association

12 April 2021

Irish Lung Fibrosis Association
www.ilfa.ie

Summary

- The National Patient Charter for Idiopathic Pulmonary Fibrosis and the Irish Thoracic Society Position Statement on the Management of Idiopathic Pulmonary Fibrosis were developed to make sure that patients with pulmonary fibrosis receive the best medical care and support services. Unlike other serious lung conditions, like cystic fibrosis or COPD, there is currently no national Clinical Care Programme for pulmonary fibrosis.

- This project set out to record patients, caregivers, healthcare professionals and industry partners' experiences around health and social care services for pulmonary fibrosis, both before and during the COVID-19 pandemic, and to capture ideas for future improvements. Seventy-two people participated in the virtual "ILFA World Café on Pulmonary Fibrosis Services in Ireland during COVID and Beyond" in April 2021.

- Our research shows there is a large gap between the recommended standard of care for pulmonary fibrosis, as per Irish Thoracic Society guidelines, and the actual care experiences of patients living with pulmonary fibrosis.

- Geographical care inequality – the "postcode lottery" - is a significant issue in pulmonary fibrosis care. For example, many patients do not have access to an Interstitial Lung Disease Nurse Specialist at their regional specialist center.

- Most patients experience significant delays in diagnosis. The lack of education and emotional support at this time causes considerable distress for patients and their families.

- Access to dietetic advice, palliative care, social support, mental health and counseling services for patients and caregivers is very poor, although use of a virtual care model has improved access to pulmonary rehabilitation during the pandemic.

- Professional mental health support is not offered to vast majority of patients or their caregivers, despite the significant impacts of pulmonary fibrosis on emotional wellbeing**.**

- There is little experience of integrated or "joined-up" care for pulmonary fibrosis across hospital and community-based services.

- COVID-19 both positively and negatively impacted patients' access to care. A hybrid or blend of face-to-face and virtual care, taking into account patient preference, could optimise care access for the future.

- The majority of care needs identified in this research would be fulfilled if the Irish Thoracic Society recommendations for the diagnosis and management of pulmonary fibrosis were implemented and resourced at national level.

- **The findings of this World Café event clearly show that a National Clinical Programme for pulmonary fibrosis is required.** There is international concern that post-COVID fibrosis (a complication of COVID-19) will place even further pressure on already stretched pulmonary fibrosis services. Urgent engagement between policy makers and other pulmonary fibrosis stakeholders is required to rapidly develop and implement a National Clinical Programme for Pulmonary Fibrosis.

Background

It is estimated that over 1,000 people in Ireland suffer from pulmonary fibrosis.[1] Pulmonary fibrosis is a serious lung condition, causing increasingly disabling breathlessness, cough, and fatigue. Pulmonary fibrosis impacts patients' quality of life and life expectancy, with a median survival time from diagnosis of 4.5 years.[2]

The Irish Lung Fibrosis Association (ILFA) is the national support and advocacy association for patients and caregivers affected by pulmonary fibrosis. Since the establishment of ILFA in 2002, we have been aware of inadequacies in care delivery for those with pulmonary fibrosis. Research conducted to inform the ILFA Patient Charter in 2015 noted difficulties in obtaining timely diagnosis and appropriate care, whilst the 2018 ILFA World Café event identified several unmet needs around the provision of palliative care for patients and caregivers.[3,4] More recently, ILFA's online survey revealed significant patient anxiety during the COVID-19 pandemic due to concerns regarding access to medical care and treatment.

It has been proposed that many of the issues around the accessibility and quality of care for pulmonary fibrosis could be resolved by the development of a national clinical care pathway for pulmonary fibrosis, as exists for other diseases. The National Clinical Programmes provide a framework for care delivery in the Irish health service, with the stated aim of improving the quality, access, and value of healthcare in Ireland.[5] There are currently 31 programmes running across multiple conditions or areas of specialty. Unlike other serious lung conditions, including COPD, asthma and cystic fibrosis, there is no National Clinical Programme for pulmonary fibrosis. The Irish Thoracic Society (ITS) has previously recommended consideration should be given to the establishment of a National Clinical Programme for Idiopathic Pulmonary Fibrosis (IPF), as stated in the 2018 update to the ITS Position Statement on the Management of IPF.[1] Despite the publication of this document almost three years ago, we are unaware of any plans to include pulmonary fibrosis in any national clinical programme, either as a separate disease or under the umbrella of respiratory medicine.

Results from an ILFA stakeholder survey conducted in 2020 showed patients, caregivers and healthcare professionals ranked advocating for a clinical care pathway for pulmonary fibrosis as the most important area of ILFA's advocacy work. The ILFA World Café on Pulmonary Fibrosis Services in Ireland during COVID and Beyond was conceived in order to document stakeholders' experiences around care access for pulmonary fibrosis, both before and during COVID-19, to better understand the challenges in obtaining and providing high quality pulmonary fibrosis care and gain insights on priorities for future care delivery.

The ILFA World Café on Pulmonary fibrosis Services in Ireland during COVID and Beyond

Following on from the success of other ILFA World Café events, this meeting style was again used to engage multiple stakeholders on unmet healthcare needs in pulmonary fibrosis. The World Café approach increases individual's participation compared to a large group discussion, ensuring each delegate has the opportunity to share their experiences and ideas.

The meeting took place on Saturday 12th April 2021. In accordance with COVID-19 restrictions this World Cafe event was conducted virtually, using video conference technology. As with a "real-life" World Café event, participants were separated into small groups in which they discussed a series of pre-defined topics for a specified time. Four topics relating to healthcare access for pulmonary fibrosis were discussed by each small group. Each topic discussion was hosted by a facilitator and a note-taker, who then rotated to a different group at the end of the allotted discussion period. The four questions posed for discussion are shown below.

World Café Topics for Discussion

DIAGNOSIS: Thinking about your own experiences, we are interested to know about the barriers you may have encountered in being diagnosed and what you think could be done to make these processes better?

HEALTHCARE SUPPORTS: Please think about any difficulties you encountered in accessing healthcare supports such as pulmonary rehabilitation, dieticians, social work support, etc. for pulmonary fibrosis, and how patient access to these services be improved as part of an overall clinical care programme?

EMOTIONAL and PSYCHOLOGICAL SUPPORT: What challenges (if any) did you encounter that prevented you from accessing emotional and psychological support for managing pulmonary fibrosis, and what would you like to see being offered to support those with pulmonary fibrosis and their families, as part of an overall clinical care programme?

CARE INTEGRATION: Is there sufficient integration of care between the hospital and the community for pulmonary fibrosis - what challenges exist that prevent you from easily accessing Integrated (community) care and virtual care. In an ideal world, what would community care integrated with hospital care look like (as part of an overall clinical care programme)?

An open invitation for all ILFA members and stakeholder to participate in the event was shared on social media. In total, 72 stakeholders participated in the meeting. This comprised 51 delegates (28 patients, 9 caregivers, 10 healthcare professionals and 4 industry representatives spanning the pharmaceutical industry, oxygen supply companies and medical technology providers) and 21 facilitators (15 healthcare professionals and 6 ILFA staff and supporters).

As well as capturing notes on experiences and ideas shared as part of the discussions, the event was also recorded to enable later analysis of themes and identification of stakeholders' priorities for future care. The essence of the event was also encapsulated through the medium of live art.

Figure 1: Some of the participants at the ILFA World Café event

Findings from World Café Event

Global Themes

Regardless of the discussion topic, there were three reoccurring themes that ran through the stakeholders' conversations.

High Unmet Care Need

As with previous research conducted by ILFA, this meeting demonstrated that there are very large unmet needs in the diagnosis and care of people with pulmonary fibrosis. The discussion revealed the vast majority of patients, and their caregivers, do not have the access to the care or the support services they require for management of their disease.

Inequality in Care Access and Quality

The issue of inequality in care access and the quality of care for pulmonary fibrosis depending on patients' geographical location arose in all discussions. Often referred to as a "postcode lottery" patients relayed significantly different care experiences depending on which interstitial lung disease (ILD) specialist center they are referred to, and the support services available to them locally. Similarly, healthcare professionals discussed differences in specialties or services available within their center or multidisciplinary team and the difficulties in referring some patients to healthcare supports in their local area.

Negative and Positive Impact of COVID-19 on Care Access

Discussion on the impact of COVID-19 on care delivery ran throughout stakeholders' conversations. COVID-19 had negatively impacted patients' access to face-to-face care and clinic assessment. However, it was noted there were also benefits arising from the greater use of new alternative models of care - with virtual pulmonary rehabilitation programmes being very highly regarded and utilised by the majority of patients. Preference for face-to-face versus virtual care differed between individuals, and there was general support for blended or hybrid face-to-face and virtual care model for the future.

Individual Discussion Topics

1: Diagnosis

Speed of diagnosis is a key issue. The time from first presentation to receiving a confirmed diagnosis for participating patients was typically around two years (and sometimes much longer). Patients largely reported relatively rapid diagnoses once a referral to a respiratory specialist service had been obtained. Those with a family history of pulmonary fibrosis typically experienced a more rapid diagnosis than others, due to a more direct referral route and diagnosis pathway.

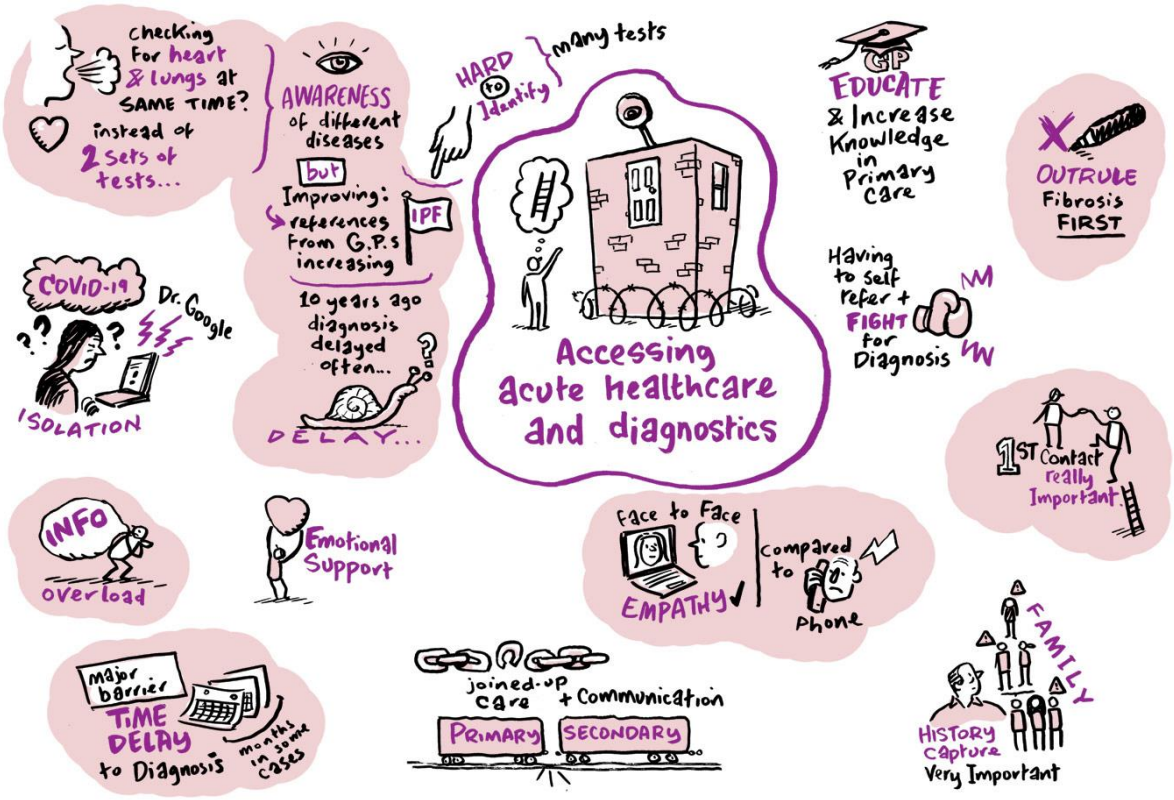

Figure 2: Artistic reportage on discussions around diagnosis.

Challenges

Lack of awareness of pulmonary fibrosis among medical professionals (GPs and non-respiratory hospital doctors) led to incorrect treatment or referral to non-respiratory services in many cases.

The route to diagnosis if often complex - many patients reported multiple interactions with healthcare services at both primary care and secondary care level for treatment and/or investigation of diverse conditions before finally being referred to respiratory services.

Lack of healthcare supports at the point of diagnosis was a key issue for many patients, including absence of disease education and emotional support and late referral (if at all) to palliative care services, pulmonary rehabilitation, and dietetics.

Solutions

Education and increased awareness among GPs have the potential to reducing the delay between first presentation and specialist respiratory referral. Redesigning the referral pathway so pulmonary fibrosis is considered as a possible diagnosis at the outset (rather than by exclusion of other conditions) was also proposed.

Centralised ILD screening and diagnostic services may improve the speed of diagnosis.

Involvement and/or referral to support services at point of diagnosis – including palliative care, pulmonary rehabilitation, dietician, social care, and mental health services would help reduce the shock and isolation patients can experience following diagnosis.

Directing patients to ILFA at diagnosis enables patients to have immediate access to peer-to-peer support and disease education.

National access to ILD Nurse Specialists and nurse led clinics is required. These were considered a "life-line" in the immediate post-diagnosis period by patients who had access to these services, but access to an ILD nurse specialist is not currently available to all.

2: Accessing Healthcare Supports

There is a very high unmet need for support services among the vast majority of patients. Whilst access to pulmonary rehabilitation has been significantly improved through use of a virtual care model during the pandemic, access to dietetic advice, palliative care, social support, mental health, and counseling services remains very poor. These services, where available, are very highly valued by patients in improving their symptom burden and quality of life.

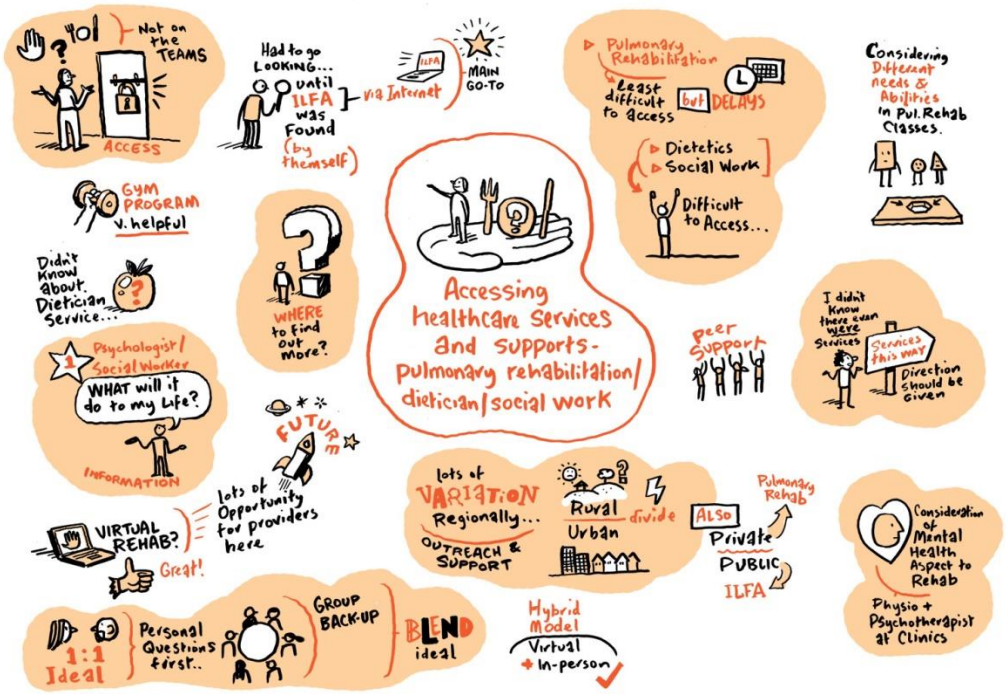

Figure 3: Artistic reportage on discussions around accessing healthcare supports.

Challenges

The absence of referrals to healthcare supports such as pulmonary rehabilitation, dietician and social worker was a common experience for many patients.

Adequate funding for support services was an issue for many healthcare professionals, who were well aware of the value of these services for patient care but had no such specialties or referral options available within their centers and/or multidisciplinary teams.

Long delays in accessing supports was the typical experience for those who had been referred to a dietician, physiotherapist or mental health service – with waiting lists of many years not being uncommon.

A postcode lottery appears to exist both in terms of supports available within each ILD specialist center and with regard to availability of community-based services in individual geographical areas.

Public versus private access to support services also differs significantly, with some patients accessing physiotherapy services privately (reimbursed by their health insurance).

A lack of patient knowledge of support services, and how to access them, exists. However, it should be noted that this is a barrier only because patients are not currently receiving early referral to such services and many instead must seek out alternative routes to access care for themselves.

Unspecialised pulmonary rehabilitation (e.g. for general respiratory conditions or often for COPD) had been offered to some patients but was perceived to be of significantly less value and benefit than a specialist pulmonary fibrosis programme.

Poor awareness among both healthcare professionals and the wider general public was proposed a possible reason why services for pulmonary fibrosis do not receive the comparable funding and policymaker focus of other serious respiratory conditions.

Solutions

A national clinical pathway for pulmonary fibrosis is required to ensure necessary support services are available, and appropriately funded, regardless of patients' clinical center or geographical location. Patients who had interactions with the National Lung Transplant Service (for lung transplant assessment or post-transplant care) reported having access to multiple high-quality support services, indicating the level of care that pulmonary fibrosis patients desire could be achieved if a programme is appropriately structured and funded.

Early referral to support services should be offered to all pulmonary fibrosis patients.

Specialised pulmonary rehabilitation should be offered to all patients after diagnosis, and ideally should be repeated to maintain patient benefits.

Virtual care had increased patients' access to online pulmonary rehabilitation during the COVID-19 pandemic. Patient feedback on this approach was very positive.

Advocacy to improve awareness of pulmonary fibrosis may positively impact healthcare resource and funding allocation.

3: Accessing Psychological and Emotional Support

All stakeholders felt that high-quality care for the emotional aspects of pulmonary fibrosis should be an integrated component of disease management.

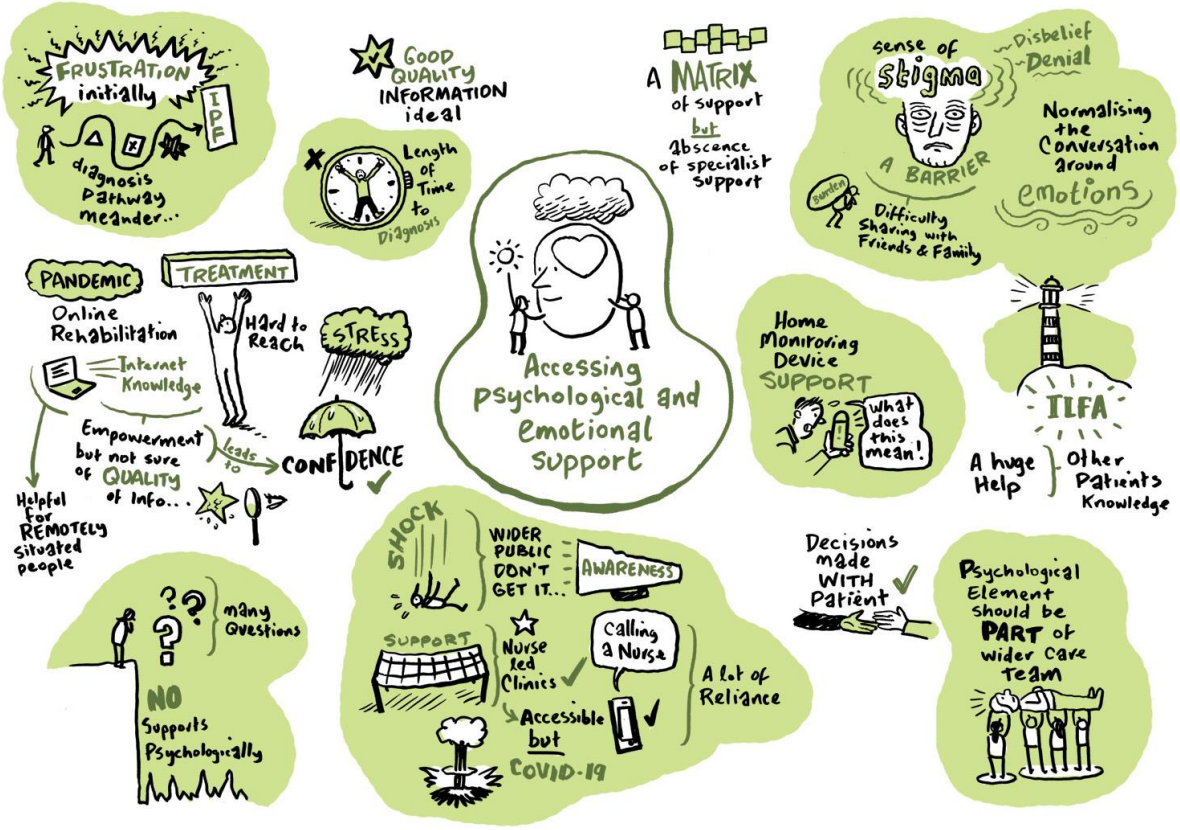

Figure 4: Artistic reportage on discussions around accessing emotional support.

Challenges

Professional mental health or emotional support is not offered to vast majority of patients**.** Many patients and caregivers rely on each other, their families and ILFA for emotional support.

Diagnosis is the cause of significant emotional distress or trauma for patients, caregivers and extended families. Most patients and caregivers report very negative experiences of receiving a diagnosis of pulmonary fibrosis, with no provision or offer of support, counseling, educational materials, or other tools.

Symptom burden is source of emotional and mental health difficulties for patients and carers.

Lack of awareness among the general population makes is more difficult for patients to discuss their disease with friends or their wider community. Lack of externally obvious symptoms in the earlier stages of the disease leads to perception among others that the disease is not "serious".

Caregivers are not considered for professional mental health supports despite the significant impacts of caring on their emotional well-being**.** There appeared to be a tendency for caregivers to want to be "strong" or positive for their loved ones, which may in turn impact their access to supports.

Stigma around mental health remains an issue in preventing some patients and caregivers from asking for help.

Disparities in care depending upon geography were also again evident. Patients treated at centers with ILD nurse specialist services, for example, were more positive about the emotional support they received from their clinical team than those who did not have access to an ILD nurse specialist.

The absence of psychological support services to which they can refer patients was keenly felt by healthcare professionals. It was observed that the nurse on the team was often left to "fill in the gaps" in mental health supports.

Respiratory team healthcare professionals feel stretched and inadequately trained in providing psychological support services to their patients.

Solutions

Support for emotional and mental health impacts of pulmonary fibrosis should be a standard part of care – both for patients and caregivers. Normalising the discussion of mental health and emotional well-being needs as part of the usual management of pulmonary fibrosis can also help to remove stigma around mental health needs.

Emotional support and counseling at the point of diagnosis is required. This could be achieved through involvement of counseling or other professional services at the time of diagnosis, or by up-skilling members of the pulmonary fibrosis multidisciplinary team in providing mental health support.

National access to ILD Nurse Specialists and nurse led clinics is needed. Patients who had access to such services found that their ILD nurse specialist is an accessible and highly valuable source of emotional support, for themselves and their caregiver.

Directing all patients to contact ILFA at the point of diagnosing ensures patients have access to highly beneficial peer-to-peer support.

High quality education aids understanding of pulmonary fibrosis and empowers patients to learn how to manage symptoms which can be beneficial in reducing anxiety and improving well-being.

Pulmonary rehabilitation provides an opportunity for peer-to-peer engagement and emotional support, as well as improving exercise tolerance and breathlessness.

Adequate resourcing and training of respiratory healthcare professionals is required so that they have the time and skills to deliver emotional support as part of a holistic care package**.**

Clinical supervision of healthcare professionals can help ensure they have the capacity to deliver care with compassion. It is recognized that burn-out is a real issue for medical staff, particularly given the demands placed on them by the COVID-19 pandemic.

4: Integrated Care and Virtual Care

There was very little understanding among stakeholders of what integrated care is, and few patients had experienced integrated care between the hospital, the GP, practice nurse and community-based services. COVID-19 had significantly accelerated the use of telephone consultations and - to a lesser extent - video consultations. Patients shared both positive and negative experiences of virtual consultations and care delivery. Patient preference for face-to-face, telephone or video consultations depended on multiple factors including access to technology, digital literacy, access to transport, location, etc.

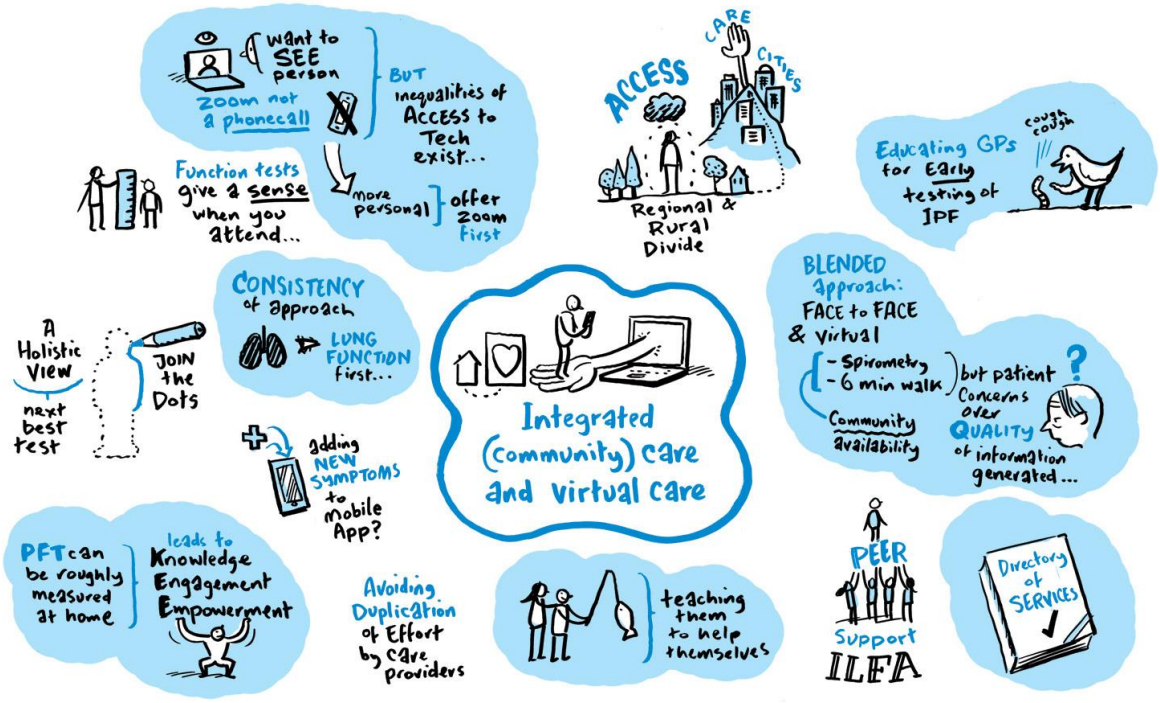

Figure 5: Artistic reportage on discussion around virtual and integrated care.

Challenges

A lack of knowledge of community-based services available to patients, and how to access them, exists.

A rural versus urban divide exists for access to community-based services, such as physiotherapy or spirometry.

The absence of a clinical pathway or framework means involvement of community services appears to be dependent on interest or availability of an individual healthcare professional.

Use of telephone consultations increases difficulties with communication, such as loss of non-verbal cues or inability to adequately involve carers, compared to video consultations.

Digital literacy, device and high-speed internet availability affects access to virtual care models.

Solutions

A directory of community-based services and how to access them would be beneficial.

An integrated IT system would enable the sharing of patient records across primary and secondary care.

Disease education for GPs and Public Health Nurses would be beneficial in ensuring integrated care for pulmonary fibrosis.

A hybrid model of virtual care and face-to-face care, taking into account patients' access and preference, was considered to be an ideal approach for the future. Video based consultations are generally preferred by patients who have access to such technology**,** improving ease of communication versus telephone consultations and offering greater convenience than clinic appointments.

Continued use of the virtual care model post COVID-19 could increase patients' access to support services. Patients who had participated in virtual pulmonary rehabilitation during the pandemic highly valued this programme.

Remote monitoring (for example home spirometry and symptom tracking) is helpful in enabling and empowering patients to self-manage their condition, and home tests can be integrated in virtual consultations.

Education to improve patient digital literacy could increase patients' access to virtual care models.

Limitations of this Research

Given the virtual format of this World Café event there is participant selection bias in favour of stakeholders that are digitally literate, and who have access to technology and high-speed internet. This may influence findings around access to virtual care. We are planning a survey to capture the experiences of a wider patient group in accessing healthcare supports.

Conclusions

In 2018, the ITS stated that the standards of diagnosis and management of IPF needed to be radically improved. The revised ITS Position Statement on the Management of IPF provided guidance to healthcare providers on the optimal diagnostic and care pathways and outlined for policy makers the resources needed to provide fair and equitable access to the standards of care that patients need and deserve.

The ILFA World Café on Pulmonary Fibrosis Services in Ireland during COVID and Beyond has shown that there is still a large discrepancy between the standard of pulmonary fibrosis care as recommended by the ITS and the experiences of pulmonary fibrosis patients and caregivers. The majority of patients still face significant delays in diagnosis. Many do not have access to an ILD Specialist Nurse. Whilst access to pulmonary rehabilitation has increased since the introduction of a virtual programme, very few pulmonary fibrosis patients who are not being assessed or managed by lung transplant services have access to dietetic, social worker, psychological or palliative care supports.

Most of the unmet care needs identified in this World Café would be fulfilled if the ITS recommendations for IPF diagnosis and management were implemented, with adequate and fair resourcing across all ILD centers. Healthcare professionals that participated in this World Café clearly expressed a desire to provide an optimal level of care for their pulmonary fibrosis patients but face numerous resourcing and/or skills barriers in doing so. Stakeholders' discussions revealed large inequalities in access and quality of care depending on patients' geographical location. Standards of care, such as access to an ILD nurse specialist or referral to a support service, differed significantly between secondary care ILD specialist centers. The findings of this World Café event therefore clearly show that a National Clinical Programme for pulmonary fibrosis is required. Patients should receive a high standard of care regardless of their location, and all ILD services need to be adequately resourced at a national level in order to achieve this.

Whilst the 2018 ITS Position Statement on the Management of IPF still represents an excellent basis for the development of a National Clinical Programme for Pulmonary Fibrosis there have been significant changes in the healthcare environment since its publication. COVID-19 has resulted in significant changes in methods of care delivery over the last 12-18

months. Participant feedback in this World Café supports use of a "hybrid model" of virtual care and face-to-face care for future pulmonary fibrosis management. Whilst we recognise not all pulmonary fibrosis patients have the required technology and internet access, virtual delivery of support services (e.g. pulmonary rehabilitation) has the potential to increase service capacity, enabling more patients to access care. Virtual consultations offer both advantages and disadvantages depending on patients' individual situations, and their use should ideally take into account patient preference. In addition, the wider roll out of Sláintecare programme also offers potential for greater involvement for community-based services in pulmonary fibrosis care. The majority of stakeholders participating in this World Café event were unsure of the services available in their community. Indeed, it would appear that without a formal programme for the management of pulmonary fibrosis there is no framework to enable the planning of integrated care for this disease. A national clinical programme for pulmonary fibrosis should therefore also consider which aspects of care and assessment could be delivered in the community, in line with the ideals of the Sláintecare initiative.

To date, pulmonary fibrosis has not received the same healthcare policy focus of other serious respiratory diseases. The prevalence of pulmonary fibrosis compared to COPD or asthma may explain some of this discrepancy, but does not appear to be the sole factor as a model of care for cystic fibrosis, a condition which affects a similar number of patients in Ireland to pulmonary fibrosis, was introduced in 2019.[6] If disease prevalence is a factor in determining the development of healthcare policy, it should be stressed that pulmonary fibrosis has recently been identified a complication of COVID-19 infection and it is expected the global burden of fibrotic lung disease will increase considerably.[6] The potential for an increase in new presentations for post-COVID fibrosis, in addition to an increasing incidence of IPF internationally, is driving a growing concern regarding the global burden of fibrotic lung disease on healthcare services.[6,7] Given this international concern, and the significant pre-existing unmet care needs in pulmonary fibrosis we have identified by our World Café event, urgent engagement between policy makers and other stakeholders is required to rapidly develop and implement a National Clinical Programme for Pulmonary Fibrosis.

Feedback on the World Café Event

Fifty-three participants (74%) provided feedback after the event. Over 96% of those who provided feedback agreed or strongly agreed that the World Cafe was helpful and 92% agreed or strongly agreed that they were able to get their views across during the event. In response to the question "What are the three things you found most useful about the workshop" there was wide agreement that the small group, multi-stakeholder approach of the World Café was a useful way of gaining insights from those on both the "user" and the "provider" side of pulmonary fibrosis services. A selection of some of the feedback regarding what participants found most useful about the event is provided below, along with a word cloud summarizing participant's choice of adjectives to describe the event.

Figure 6: Quotations of participants' feedback regarding what they found most useful about the World Café and a "Word Cloud" of participants' adjectives to describe the event.

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Next Steps

ILFA will work with the Irish Thoracic Society in advocating for further advances in care for pulmonary fibrosis patients and caregivers. We plan to use the results of this research as evidence for inadequacies in care delivery for pulmonary fibrosis in our engagements with policy makers and politicians.

Acknowledgements

ILFA would like to thank all stakeholders who participated in this World Café Event.

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Thank you to our speakers who provided their insights, expertise, and entertainment during the meeting, in addition World Café discussion component of the event:

Michael Darragh Macauley, ILFA Ambassador, who led us in a live guided breathing exercise.

Dr Eoin Judge, Respiratory Consultant at Connolly Hospital, who provided us with a summary of the ongoing recovery of healthcare services for pulmonary fibrosis as the COVID-19 vaccination programme accelerates.

Professor Gaye Cunnane, Director of Health and Wellbeing at the Royal College of Physicians of Ireland, who shared her highly valuable insights about the importance of tolerance, self-compassion, and hope in maintaining wellbeing during the pandemic.

Dr Anne-Marie Russell, Senior Lecturer University of Exeter, UK, who opened the World Café discussions and led the closing panel discussions on participants' feedback.

Moya Brennan, singer, and songwriter, who lifted us all with her beautiful voice.

Harry Carpendale, harpist, who performed a wonderful piece he had composed specifically for ILFA members and friends.

Tony Shone and Marco Santorini from Invisio Ltd. for supporting the World Café with facilitation and technology.

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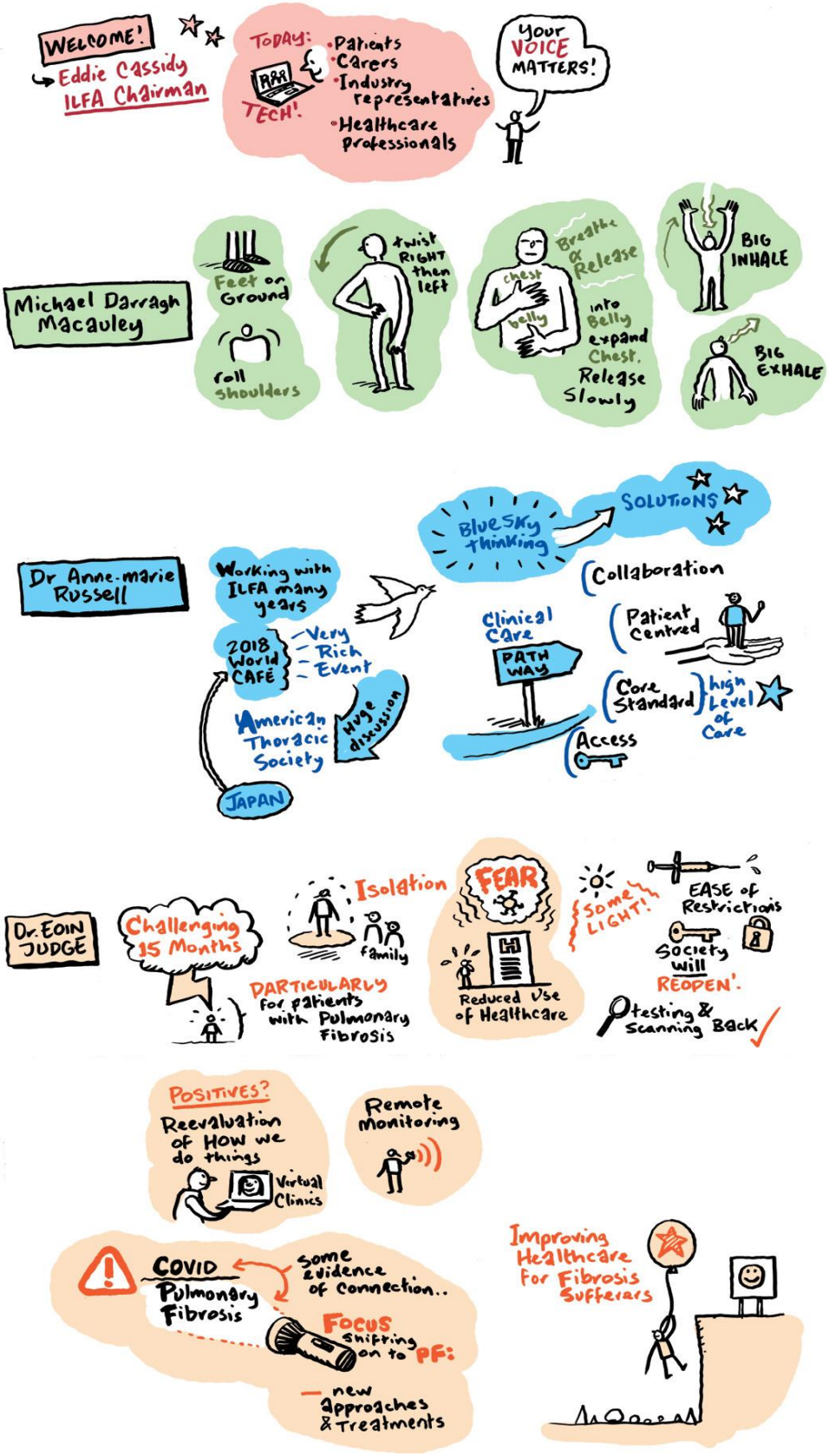

Figure 6: Artistic reportage on some of the presentations at the World Cafe.

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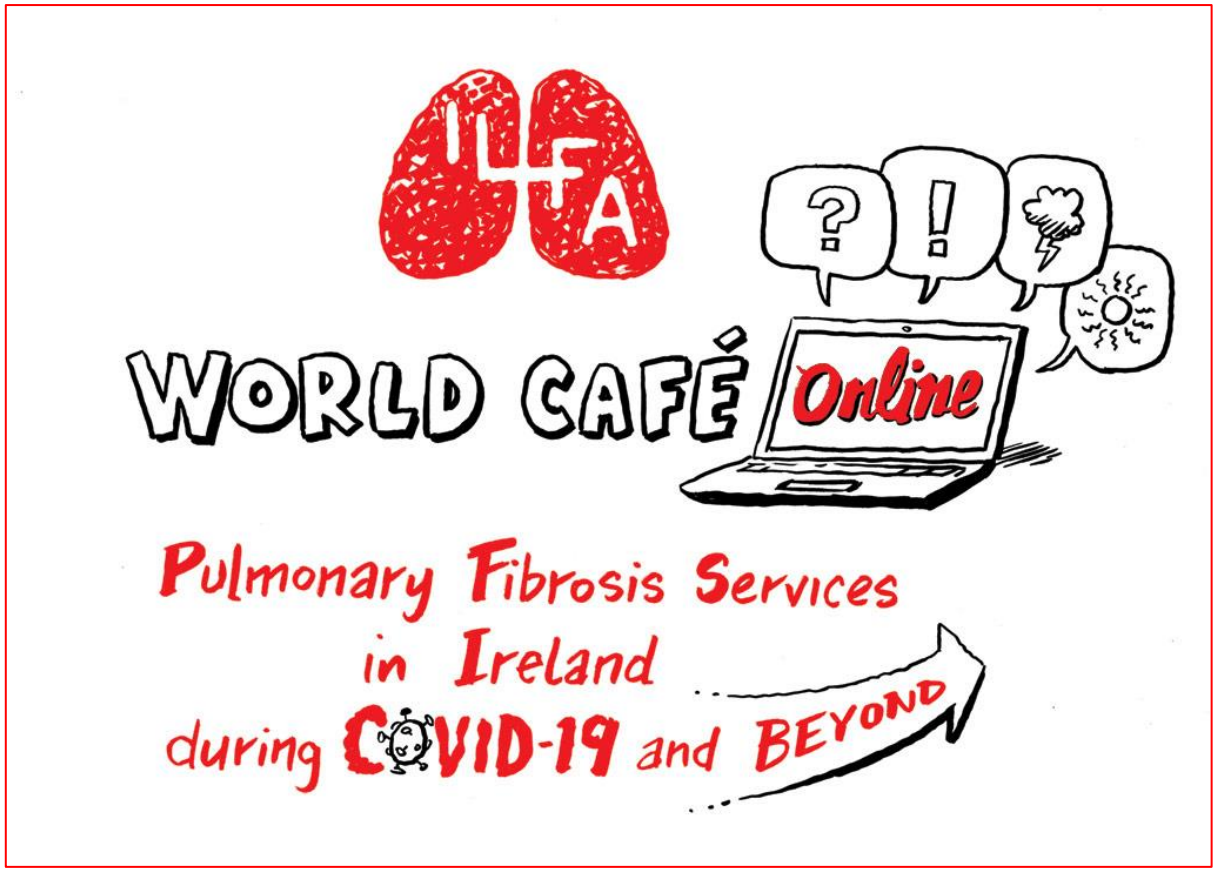

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