Irish
Medical
Journal
Established 1867

Issue: Ir Med J; Vol 114; No. 7; P410

Perspectives of Interstitial Lung Disease Patients and Carers During COVID-19

N. Cassidy[1], D. Sheahan[2], L. Fox[1,3], L. Brown[1,4], L. Galvin[1],
E. Cassidy[1], M. Sheridan[1], G. O'Dowd[1] K.M.A. O'Reilly[1,3]

1. The Irish Lung Fibrosis Association, Dublin, Ireland.
2. Invisio Ltd., Blessington, Co. Wicklow, Ireland.
3. Mater Misericordiae University Hospital, Dublin, Ireland.
4. St. Vincent's University Hospital, Dublin, Ireland.

Abstract

Aim

To gain an understanding of the impact of COVID-19 on the daily life, healthcare needs, mental wellbeing and outlook of patients with Interstitial Lung Disease (ILD) and their caregivers.

Methods

ILD patients and caregivers were invited to participate in a quantitative survey. Respondents could self-select to then participate in in-depth structured telephone interviews. Survey data was compared to Department of Health COVID-19 public opinion tracker findings for the comparable time period.

Results

There were 170 survey respones (111 patients and 59 caregivers) and 14 in-depth interview participants. 32% (n=36) of patients and 42% (n=25) of caregivers expressed extreme worry regarding COVID-19 on a 1-10 scale. 83% (n=92) of patients expressed concern about safe hospital access, 33% (n=37) had received a telephone consultation with their clinician, 43% (n=48) reported test delays, 47% (n=52) were exercising less, 23% (n=26) reported worse sleep and 15% (n=17) reported being financially worse off. Carers reported that sleep was worse for 58% (n=34), 42% (n=25) reported being worse off financially, and 40% (n=24) reported a worse diet. Worry (66%, n=39), stress (51%, n=30), anxiety (49%, n=29) were commonly reported by carers.

Discussion

ILD patients and caregivers reported higher levels of worry regarding COVID-19 compared to the general public. Alternative pathways for quality ILD patient care and interventions to reduce the burden of care on ILD caregivers are required.

Introduction

Interstitial lung disease (ILD) is an umbrella term for a number of disorders associated with lung fibrosis. ILDs are characterised by increasingly disabling breathlessness, cough and fatigue with progressive impacts on patients' activities of daily living and quality of life (QoL). Idiopathic pulmonary fibrosis (IPF), the most prevalent ILD, is estimated to affect around 1,000 patients in Ireland, with median survival from diagnosis of 4.5 years.[1,2]

ILD patients are highly medically vulnerable to coronavirus (COVID-19).[3] Overall mortality in ILD patients hospitalised with COVID-19 in an international multi-centre study was 49%, significantly higher than matched controls (HR 1.6, $p<0.003$).[4] In April 2020 Irish authorities issued advice that ILD patients should "cocoon", i.e. stay at home and avoid physical contact with others.[5]

The Irish Lung Fibrosis Association (ILFA), a patient organisation founded to support patients and families affected by ILD, conceived and supported this research in order to gain a deeper understanding of the impact of the COVID-19 pandemic on ILD patients, their caregivers and healthcare professionals working in this field. Here we focus on the results from ILD patients and caregivers, data from healthcare professionals has been previously reported in this journal.[6] Our findings have implications not just for our own organisation, but also for clinicians working in this field.

Methods

We conducted quantitative and qualitative research, in the form of survey questionnaires and in-depth structured telephone interviews, with ILD patients and informal caregivers and/or family members of ILD patients. The aim was to gain greater understanding of the impact of the COVID-19 pandemic on daily life, healthcare needs, mental wellbeing and future outlook of ILD patients and caregivers.

ILD patients and caregivers were invited to participate in a survey via an email/letter from ILFA to its stakeholders and postings on ILFA's social media. The surveys (online or via telephone if required) were designed to collect information on respondents' demographics, worry in relation to COVID-19, impact on daily living and access to healthcare, emotional well-being, level of support, use of technology, future implications and ILFA's advocacy priorities. Those who had completed the survey could self-select to participate in a telephone interview. Interviews were conducted by independent research professionals and were structured to address cocooning, basic daily needs, healthcare needs, communication, effect on mental wellbeing, supports from HSE and other organisations, long term implications and any other concerns. Interviews were recorded and transcribed for thematic analysis.

We compared findings from our research to data from the Department of Heath COVID-19 Public Opinion Tracking Research, which measured worry in relation to COVID-19 in 1,500 adults at a comparable time point (20th April 2020).[7]

Results

The survey research was conducted from April 16th to May 5th, 2020. Survey responses were gathered from 111 ILD patients and 59 informal caregivers. Seven ILD patients and seven caregivers participated in structured in-depth telephone interviews, conducted from April 28th to May 20th, 2020.

Demographics

Table 1: Patient and Caregiver Demographics.

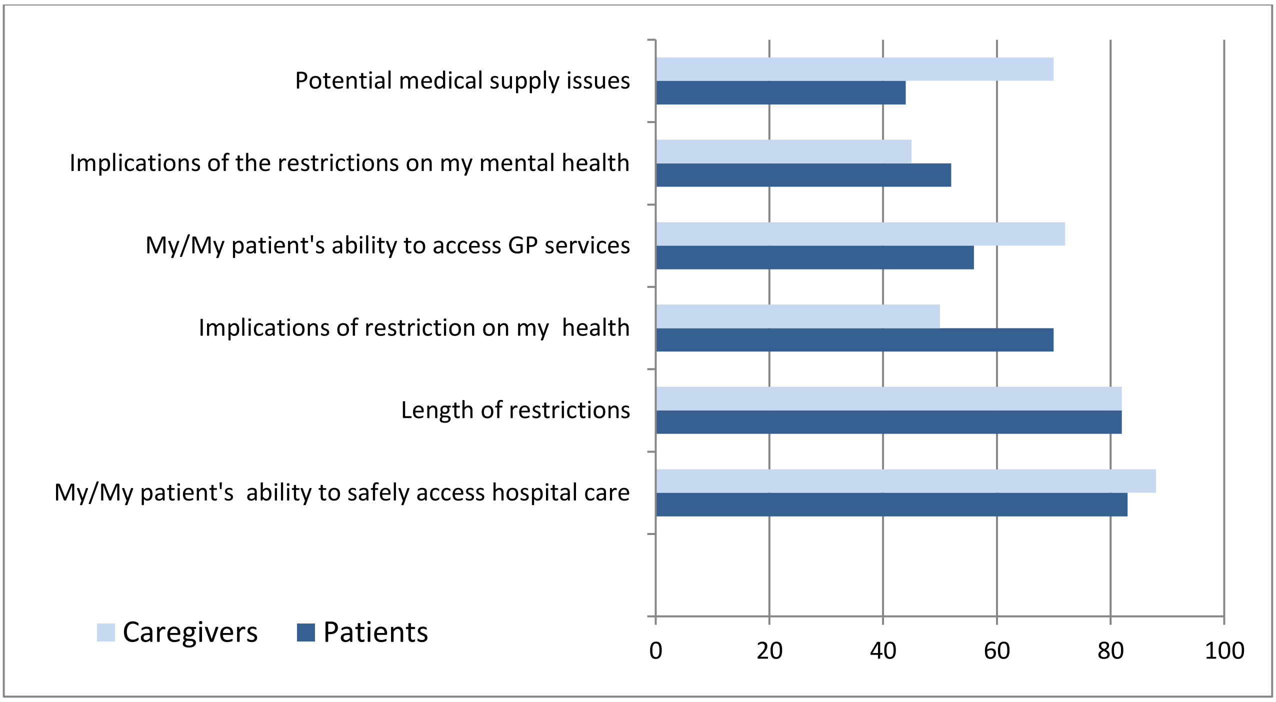
	All Patients (n=111)		**Caregivers (n=59)**	
	N	%	N	%
Male	63	57	8	14
Age Category:				
18-60 years	26	23	44	75
61-70 years	42	38	11	19
71+ years	43	39	4	7
Receiving supplemental oxygen	37	33		
IPF Diagnosis	89	80		

Reported Worry about COVID-19

On a scale of 1 (not at all worried) to 10 (extremely worried), 32% (n=20) of patients and 42% (n=25) of caregivers were extremely worried about COVID-19. The average worry rating was 7.4 and 8.1 in patients and caregivers, respectively. The most common worry for patients was contracting COVID-19 (74%, n=47), for caregivers it was the health of family and friends (90%, n=53). When asked to indicate their level of concern regarding particular topics (figure 1), 83% (n=52) of patients were concerned about their ability to safely access hospital care if needed, with 88% (n=52) of caregivers sharing this concern for the patient they cared for.

Three quarters of patients were reassured by the Government's response to COVID-19, and although 74% (n=47) were confident of the ability of the health service to meet society's needs during the outbreak only 62% (n=39) were confident in its abilities to meet their own healthcare needs.

Figure 1: Sources of Reported Concern for Patients and Caregivers*.



**Percentage of patients and caregivers a little or very concerned about each issue*

Impact on Daily Living

Almost half (47%, n=30) of patients were exercising less since the COVID-19 measures began, this increased to 65% (n=41) for those living in Dublin, but 14% (n=9) were exercising more. Almost one quarter (23%, n=14) reported worse sleep and 15% (n=9) were financially worse off. For carers, sleep patterns were worse for 58% (n=34), 42% (n=25) were worse off financially, and 41% (n=24) reported eating a worse diet. Telephone interviews found that carers were either cocooning themselves or were limiting themselves to essential excursions.

Impact on Access to Healthcare

Since the COVID-19 restrictions began, 33% (n=21) and 43% (n=27) of patients had received a telephone consultation with their hospital respiratory team and GP, respectively. Only 11% (n=7) of patients had tests carried out as planned, 40% (n=25) of those had experienced delays in obtaining results, and 43% (27) had tests delayed. Two thirds were happy with their direct medical care, with the remainder indicating they needed additional support around individual patient specific issues (6%, n=4), oxygen concerns (6%, n=4), updates on tests and progression of condition (5%, n=3), or more GP communication or support (5%, n=3), amongst other issues.

Interviews revealed that cancellations or delays with medical appointments were a source of anxiety for patients. Patients who had received telephone consultations were generally happy with this service, although there were concerns regarding access to lung function tests and the subtle differences of face to face versus telephone communication.

All patients interviewed were reluctant to attend hospital if they needed to, or had already had a situation where they avoided the hospital: *"If I was told during a consultation* (with GP) *that I had to go to the hospital, I would go but I would be very apprehensive about going to the hospital. I'd take any move possible, rather than actually go into a hospital as of now*."

Support

Forty-four per cent of patients (n=28) indicated no additional supports were required from ILFA, compared to 33% (n=19) of caregivers. The most commonly identified area for additional ILFA support among patients was to continue to advocate for patients and raise awareness of ILDs (13%, n=8), whereas for caregivers this was to keep in touch (17%, n=10). In interviews patients were largely happy with supports available from either the HSE or other organisations, but two caregivers identified a need for counselling services: "*A counselling service that understand what you're going through"* and "*I think where a lot of services fall down they don't have counsellors. They just need someone to talk to that understands and not a family member because they can't really say what they think and feel."*

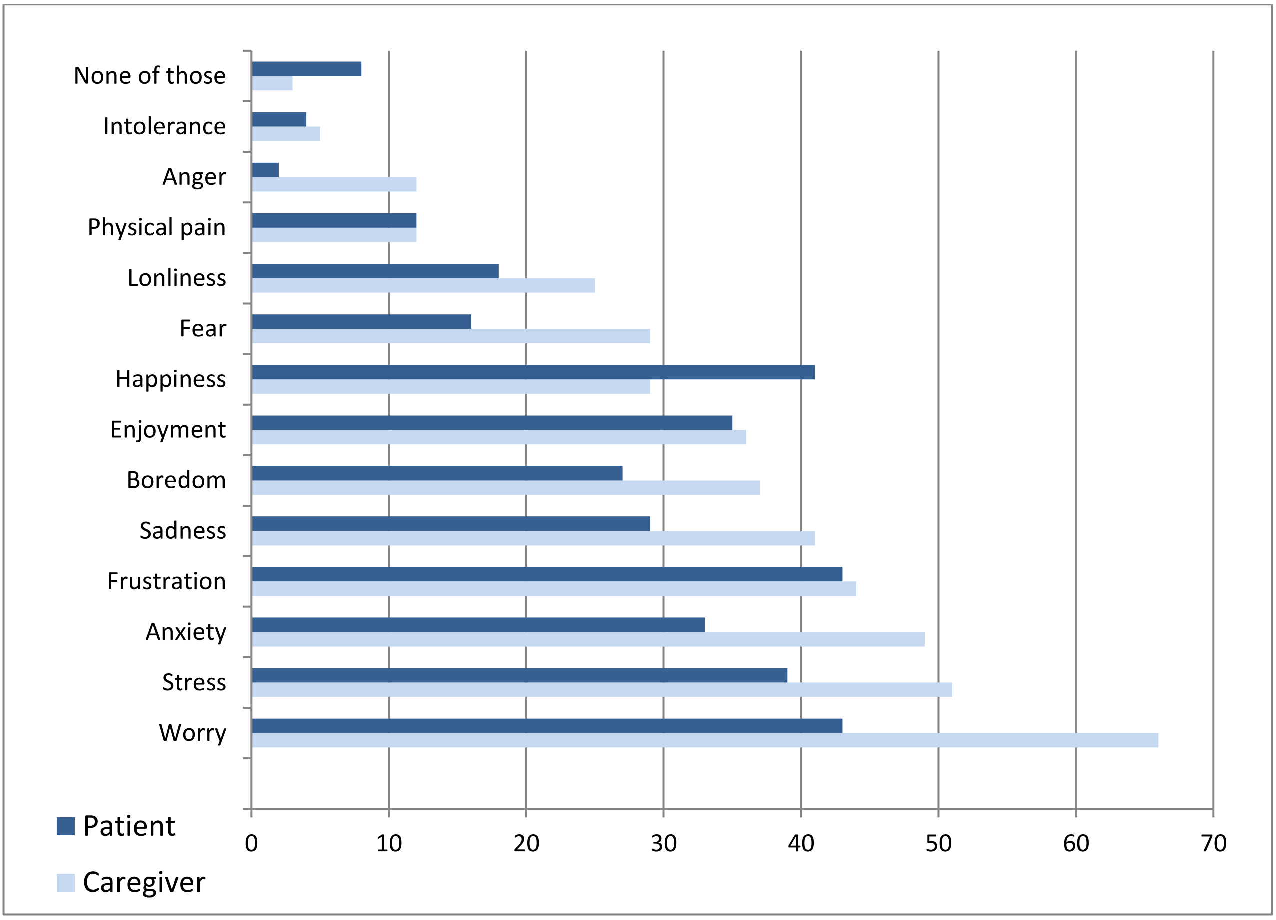
Use of Technology

Whilst smart phone ownership amongst patients was high (80%, n=50), this dropped to 64% (n=40) in the over 70s cohort and 5% (n=3) of all patients did not have access to either a smartphone, tablet or a laptop. Almost two-thirds (63%, n=40) of patients used phone-based apps to help them in their daily life.

Emotional Wellbeing

Almost half (46%, n=29) of patients reported feeling happiness in the day preceding the survey, but multiple negative emotions were also reported, including anxiety (33%, n=21), sadness (23%, n=15) and loneliness (11%, n=7). Few carers reported feeling positive emotions, with worry (66%, n=39), stress (51%, n=30), anxiety (49%, n=29), frustration (44%, n=25), sadness (41%, 24) and boredom (37%, n=22) being more commonly reported than either enjoyment (36%, n=21) or happiness (29%, n=17).

Figure 2: Patient and Caregiver Emotions^.



^Percentage of Patients and Caregivers who reported experiencing each feelings "a lot" on the preceding day of the survey

Long Term Implications and Future Care Planning

Over half of patients surveyed (56%, n=35) had not discussed treatments that they would not like to receive in the event of them becoming seriously unwell, with 32% (n=20) having such discussions with close family and 11% (n=7) with healthcare professionals. Most (65%, n=41) were not aware of the Irish Hospice Foundation's Think Ahead document on end of life planning, and only 3% (n=2) had completed it. Several patients interviewed expressed grave concerns about the long term impact of COVID-19 on their future: ***"****Truthfully, I'm only praying to God that I live through it"* and *"If we don't start doing transplants in the next 12 months... the window for me… that's not a good situation. It's a tragic situation."*

Advocating for Change

When asked to prioritise areas of ILFA's advocacy work, patients and caregivers ranked advocating for a clinical care pathway for lung fibrosis as the most important (figure 3). This was consistent across all patient demographics.

Figure 3: Prioritisation of Areas for Patient Advocacy Ranked by Patients and Caregivers†.

Area of Advocacy	Patients	Caregivers
That lung fibrosis has its own clinical care pathway like cancer	1.8	2.3
Promoting more awareness of the condition among GPs	3.0	3.2
More access to pulmonary rehab	3.2	3.4
Promoting more awareness of the condition among hospital staff	3.9	3.9
Promoting more awareness of the condition among the wider public	4.1	4.5
Improving access to oxygen supplies	4.7	3.7

†Average importance ranking where 1 = most important, 5 = least important.

Discussion

This research was conducted during severe national COVID-19 restrictions in Ireland. Reported worry regarding COVID-19 among ILD patients and caregivers was higher than that of general public during the comparable period (average rating of 7.4 and 8.1 versus 6.6, respectively).[7] The ability of the ILD patients to safely access hospital services was a key concern. Less than two-thirds of ILD patients were confident in the health service's abilities to meet their healthcare needs, and all patients interviewed were reluctant to attend hospital. This has serious ramifications for both scheduled and emergency ILD patient care, including the management of acute exacerbations or other potential outcomes arising from ILD patients' significant co-morbidities.[8] A 45% reduction in emergency department (ED) presentations during COVID-19 restrictions was observed in Ireland, comparable to that reported in the US.[9,10] Research from one US centre indicated that patient reluctance to attend the ED was due in part to lack of awareness of the hospital's risk mitigation strategies, and a need for clinician reassurance regarding when to attend.[11] ILD patient education materials detailing hospitals' procedures for COVID-19 risk mitigation, the importance of attending acute services if required, along with advice on when to attend hospital, may help to address such concerns and reduce the downstream repercussions of hospital avoidance.

There were unmet needs in the continuity of care for ILD patients at this time, with one third indicating they needed additional support and only 33% (n=21) having had a telephone consultation with their hospital respiratory team. Delays in consultations, assessments, or receiving test results were a source of concern, and alternative pathways for quality ILD patient care are required. Although telephone consultations were not considered optimal for ease of communication, or where assessments were required, telemedicine was generally well accepted by patients. Given the reluctance of patients to access hospital services, ILD healthcare professionals should consider optimisation of telemedicine during the pandemic. Concerns have previously been raised regarding the use of telephone communication with geographically isolated ILD patients, due to the exclusion of carers and the lack of visual clues potentially adversely affecting recognition of anxiety, depression or appreciation of patients' understanding. Such geographical isolation is analogous to the COVID-19 situation and multi-disciplinary ILD team video consultations have been proposed as a superior approach to remote care.[12]

In terms of remote assessments; use of digital platforms to record home spirometry in IPF patients has been shown to be feasible, and can provide a reliable estimate of lung function once attention is given to technique.[13] Whilst usage of smartphones was high among patients, it did decline in those over 70, and some may need assistance with technology.

Markers of emotional distress and negative impacts on daily life were more common among caregivers than patients. Previous research has shown that caregiving for ILD patients significantly impairs health related QoL, particularly emotional health.[14] Novel interventions are required to reduce the burden of care and improve the QoL of ILD caregivers during the pandemic, with implications for both patient organisations and the multidisciplinary ILD team. Caregivers identified that counselling services would be helpful, and professional psychological supports for those with ILDs could potentially be extended to include caregivers. Further studies are required to assess the relative effectiveness of strategies to support caregivers.

It was evident that patients are aware of the implications of the pandemic on their futures. Despite this, few patients had discussed their preferences around care should they become seriously ill. Research has shown that there are multiple inadequacies in palliative care of patients with ILDs, with deficiencies in advice or education on how to approach future care and end of life planning being just one aspect of this.[15]

Whilst many of the findings of this research relate to new issues brought about by COVID-19, some themes, including the burden of caregiving and inadequacies in palliative care, have previously been identified.[16] Patients and caregivers agreed that campaigning for a clinical care pathway for ILD was the most important area of ILFA’s advocacy work. In line with this mandate, ILFA will continue to advocate for change in this area for the benefit of ILD patients, carers and healthcare professionals - to meet both pre-existing challenges and new issues arising from the COVID-19 pandemic.

Declaration of Conflicts of Interest:
The authors have no conflicts of interest to declare.

Corresponding Author:
Nicola Cassidy,
Irish Lung Fibrosis Association,
PO Box 10456,
Blackrock,
Co. Dublin,
Ireland.
E-Mail: info@ilfa.ie

References:

1. Tran T, Šterclová M, Mogulkoc N, Lewandowska K, Muller V, Hajkova,M, et al. The European MultiPartner IPF registry (EMPIRE): Validating long-term prognostic factors in idiopathic pulmonary fibrosis. Respir Res 2020; 21: 11.
2. Irish Thoracic Society. Irish Thoracic Society Position Statement on the Management of Idiopathic Pulmonary Fibrosis. https://irishthoracicsociety.com/wp-content/uploads/2018/08/ITS-Pulmonary-Fibrosis-Position-Statement.pdf (accessed 21.09.2020)
3. Crisan-Dabija R, Pavel CA, Popa IV, Tarus A, Burlacu A. "A Chain Only as Strong as Its Weakest Link": An Up-to-Date Literature Review on the Bidirectional Interaction of Pulmonary Fibrosis and COVID-19. J Proteome Res. 2020; 19: 4327-4338.
4. Jenkins G, Drake T, Docherty AB, Harrison E, Quint J, et al. Outcome of hospitalisation for COVID-19 in patients with Interstitial Lung Disease: An international multicentre study. American Journal of Respiratory Care 2020; 202:1656-1665.
5. Health Service Executive. People at Higher Risk of COVID-19. Last updated 25 September 2020. Available from: https://www2.hse.ie/conditions/coronavirus/people-at-higher-risk.html. Accessed on 2nd October 2020.
6. Cassidy N, Sheahan D, Fox L, Brown L, Galvin L, Cassidy E, et al. (2021). Perspectives of Interstitial Lung Disease Patients and Carers during COVID-19. Irish medical journal, 114(5), P361.
7. Department of Health. Coronavirus Public Opinion Tracking Research. 4th May 2020. Available from: https://assets.gov.ie/73911/25d65090b99245978312006474518 7c6.pdf. Accessed on 2nd October 2020.
8. Raghu G, Amatto VC, Behr J, Stowasser S. Comorbidities in idiopathic pulmonary fibrosis patients: a systematic literature review. European Respiratory Journal 2015; 46: 1113-1130.
9. Brick A, Walsh B, Keegan C, Lyons S. Economic and Social Research Institute Special Article: COVID-19 and emergency department attendances in public hospitals. Undated. Available at: https://www.esri.ie/system/files/publications/QEC2020SUM_SA_lyons.pdf Accessed on 2nd October 2020.
10. Hartnett K, Kite-Powell A, DeVies J, Coletta MA, Boehmer TK, Adjemian J, Gundlapalli AV. Impact of the COVID-19 Pandemic on Emergency Department Visits — United States, January 1, 2019–May 30, 2020. Morbidity and Mortality Weekly Report. 2020; 69(23): 699–704.
11. Wong LE, Hawkins JE, Langness S, Murrell KL, Iris P, Sammann A. Where Are All the Patients? Addressing Covid-19 Fear to Encourage Sick Patients to Seek Emergency Care. NEJM Catalyst [Digital]. 2020 May 14. Available from: https://catalyst.nejm.org/doi/full/10.1056/CAT.20.0193#
12. Cassidy N, Powell P, Wells AU. Patients with idiopathic pulmonary fibrosis: Overcoming "geographic isolation". Respirology 2020; 25(10): 1029-1020.
13. Fox L, McLeod L, Russell A-M, Edwards C, O'Reilly KMA. An Observational Study of Self-Monitoring of Spirometry and Symptoms via a Mobile Electronic Health Journal in Usual Care of Patients with Idiopathic Pulmonary Fibrosis. American Journal of Respiratory and Critical Care Medicine 2020;201:A3394.

14. Shah RJ, Collard HR, Morisset J. Burden, Resilience and coping in caregivers with interstitial lung disease. Heart Lung. 2018;47: 264-268.
15. Kreuter M, Bendstrup E, Russell AM, Bajwah S, Lindell K, Adir Y, et al. Palliative care in interstitial lung disease: Living well. Lancet Respir Med. 2017; 5: 968-980.
16. Irish Lung Fibrosis Association. Palliative Care and Planning for the Future: World Café Report. 9th June 2018. Available at: https://www.ilfa.ie/docs/ILFA%20World%20Cafe%20Report%20FINAL2019.pdf Accessed on 9th October 2020.