healthwatch Bristol

healthwatch South Gloucestershire

CARING FOR SOMEONE WITH DEMENTIA:

A UNIQUE JOURNEY

May 2021

"It's a whirlwind of sadness and anger, frustration.
I am full to the brim all the time" - J.

Contents

Narrative themes

Survey findings

In their own words

Introduction

At Healthwatch South Gloucestershire and Healthwatch Bristol we listen to patient experiences, base our work on those experiences and inform commissioners and providers about good practice and areas for service improvement. Our 'Caring for someone with dementia: A unique journey' report summarises the feedback we have heard from local people about caring for someone with dementia, how that feels and what improvements those we spoke to would like addressed.

About Healthwatch

Our statutory duty and remit, under the Health and Social Care Act 2012, is to provide a voice for people who use health and adult social care services. We give people an opportunity to have a say about these services, including those whose voice is not usually heard, and we report the views to inform those providing services and improve care pathways. This means taking public views to influence the people who make decisions - we have a representative on the respective Local Authority Health and Wellbeing Boards and share feedback themes and narrative to government via Healthwatch England, the Care Quality Commission (CQC) and relevant local providers and commissioners.

Our outcomes are tracked against a set of key performance indicators by our commissioners at Bristol City Council and South Gloucestershire Council. Our 2019-2024 contract states; "***Healthwatch is committed to promoting equality, and diversity and tackling social exclusion in all our activities. We aim to ensure equitable access to our initiatives and projects.***"

Executive Summary

Healthwatch Bristol and Healthwatch South Gloucestershire have collected feedback from local citizens relating to Carers support and interviewed participants with lived experience of caring to help understand what matters most to those effected by caring for someone with dementia and the services available to support this.

We found several key themes emerged around information, language, and emotional challenges but more importantly we discovered the uniqueness of each person's story and how an understanding of that is essential to improvements in support and wellbeing.

Our findings show that Carer’s experiences and needs are varied but do fall into broad themes:

Ethnically sensitive and tailored care for dementia patients would help to ease the burden for the carer by removing the need for the family carer to be present whilst the patient received paid care.

If Carers were able to access flexible appointments to fit with caring commitments, there would be fewer missed opportunities to support Carers needs.

Carers often feel overwhelmed with information and appointments from different places after diagnosis.

Carers told us that counselling is not universally offered and that respite is essential for their mental wellbeing.

Younger Carers expressed feeling more isolated and less well served.

Female carers said they were able to discuss their feelings and ask for emotional support, but male carers said they did not.

Carers said they would like honest conversations that helped them form a clearer picture of the journey ahead.

Those Carers without family support struggled with emotional issues.

Background

Dementia can take many forms and is a debilitating syndrome stemming from several different causes. It involves a progressive decline in areas of cognitive competency and can include, but is not exclusive, to loss of memory, deterioration of reasoning and impaired communication skills. The length of the progressive pathway is unpredictable and non-linear, with an inevitable decline in function and the increasing need for care.

Over 7% of people over the age of 65 in the UK today have been diagnosed with dementia, in Bristol this equates to nearly five thousand people and about two thousand in South Gloucestershire (Ref 1 and Ref 2). It is thought that 40% of all dementia care is unpaid and provided by family or friends within the home (Ref 3). In Bristol and South Gloucestershire alone, it is estimated that Carers save health and social care services £1.19 billion every year by providing unpaid care (Ref 4).

Carers do not want to be defined by their role and have a unique voice separate and yet entangled with those they care for. The need to appreciate their needs and the challenges they face has been amplified by the Covid-19 restrictions, with many carers providing sole care for a loved one 24 hours a day, seven days a week. Dementia Carers' wellbeing is at the heart of a good care system and strong positive mental health initiatives are required to support them throughout the journey.

"Loving someone helps, resilience is essential, make small goals - the hardest thing is that sometimes he is better again and the hope hurts so much" - J (59) caring for her husband.

Aims and Objectives

Our main purpose was three-fold; to find out what matters to Carers so their views shape the support they need, amplify the voices of those we spoke to and create a tailored resource for those in need of direction to services. Additionally, we were interested in addressing differences, inequalities and variety across our communities and actively sought the participation of carers from ethnically diverse groups.

Our project focus shifted during the scoping stage in response to input from our co-production partners. However, our aims remained clear. The intention was to engage in a partnership of co-design and to establish what mattered most to those involved. We are committed to the project outcomes and recommendations being firmly led by a local perspective and to this end enlisted the skills and knowledge of dementia care professionals in Bristol and South Gloucestershire, all of whom provide existing and popular services (Appendix 1). We enlisted the help of group mentors with lived-experience and the experts – the Carers themselves. Our initial objective was to discover what worked well and to investigate where positive pathways were already accessible to all.

Secondly, we looked at what the Carers would ideally like to see and what was missing in their experience. The aim was to create research and report on experiences that genuinely reflect the Carers journey, ultimately learning from their reality. We have built a highly adaptable resource that matches the need for support in real time and has a local focus. We aim to continue the co-production ethos by maintaining an ongoing partnership between people who design and deliver services and the people who need them.

Methods

An initial literature review was conducted to ascertain baseline findings around Carers emotional outcomes and the impact that dementia care at home has on wellbeing and relationships. This was followed by a local resource audit and mapping of statistical data to investigate how the offer that is currently available meets Carers' support needs. This was completed across a variety of communities with specific focus on diversity and inclusion.

A process of co-design consultation was undertaken with organisational representatives and with lived-experience participants to create the focus group events, form the questions, and suggest resource formats.

A stakeholder's event was held online which provided further insight into the availability of support geographically. This afforded us the opportunity to engage in a co-production approach based on information from service delivery professionals who work closely with dementia patients and Carers. Reciprocal agreements were formed whereby later resource development could be substantiated with interested parties. There was also a series of one-to-one stakeholder meetings.

A second event for those with lived experience was arranged via the Zoom platform with themes and discussions around service gaps and best practise were recorded. Co-production agreements were made with an informal steering group regarding the project direction and outcomes.

We used a set of standardised questions at our initial events, and also in the later meetings and interviews. This helped us collect statistical data.

A series of interviews with Bristol and South Gloucestershire based carers were undertaken on the telephone, taking between 30 minutes and one hour. Conversation prompts were agreed prior to this and replicated at each interview, but open narrative discussion was actively encouraged.

The recommendations and resource design and material were evaluated by the co-production members prior to reporting and distribution.

"Carers need time for themselves too, so you can still be yourself. You need people to acknowledge your experience and…the professionals need to listen. Being heard is really important." - (T.) caring for his wife.

The Caring Journey - Our Findings

Carers shared their experiences, which we found fitted broadly into these narrative themes:

1. The Emotional Challenge

"So many Carers feel embarrassed if the person they care for has done something out of the ordinary in public." - focus group.

2. Acceptance

"People want acknowledgement that they have been heard." - focus group.

"Overprotection issues can cause conflict between family and Carers." - focus group.

"It takes time for Carers to come to terms with the diagnosis, living with the fears and worries for the future, the unknown, and taking responsibility for the family." - focus group.

"It is also about society becoming more willing to talk about it." - focus group.

3. Acknowledge Uniqueness

"There is a misconception that a lot of ethnic minority communities live in the central of Bristol, because of this GP's may not know about many support groups for those Carers in the outer areas of Bristol." - focus group.

"Service provision still does not respect BAME differences and is too mainstream"- focus group.

3. The Importance of Language

"Carers identify with the term 'supporting someone who is unwell' better." - focus group.

"There are many barriers (language, cultural understanding, visibility) stopping people from accessing support, or missing out on accessing services." - focus group.

There is clear evidence that access to services isn't equal to everyone in society." - focus group.

"It has been a struggle getting the terminology right as it can feel like me, the Carer is being assessed, therefore it can be intimidating."- focus group.

4. Peer Support

"Telephone support is very important as people can access it without having access to the internet. Often Carers just want someone to talk to more than any other help." - focus group.

"There is currently a waiting list for telephone befriending and counselling." - focus group.

"The opportunity to mix with fellow Carers at Carers support groups are incredibly helpful as they help to share common experience in a safe, confidential space." - focus group.

"Carers are the experts. Unfortunately, going to a group is a huge hurdle to many Carers. It is therefore important to also do 1:1, face to face." - focus group.

5. Respite

"I think services aren't there ... or people aren't aware of them - there is more to be done to make people aware of services." - focus group.

" *We were never told about any respite options"* - Carer (Chinese community*).*

"Just shopping recharges my batteries, although then I feel guilty for being away and even guilty that I feel better, but then I am nicer so we both benefit." - Carer.

6. Choice

"Carers struggle with being inundated with information." - focus group.

"Knowing how to access the information is important. It is about being confident to call and find out the information you require." - focus group.

"We are focusing on finding positive things, this is really important when you do not have lots of choices." - Carer.

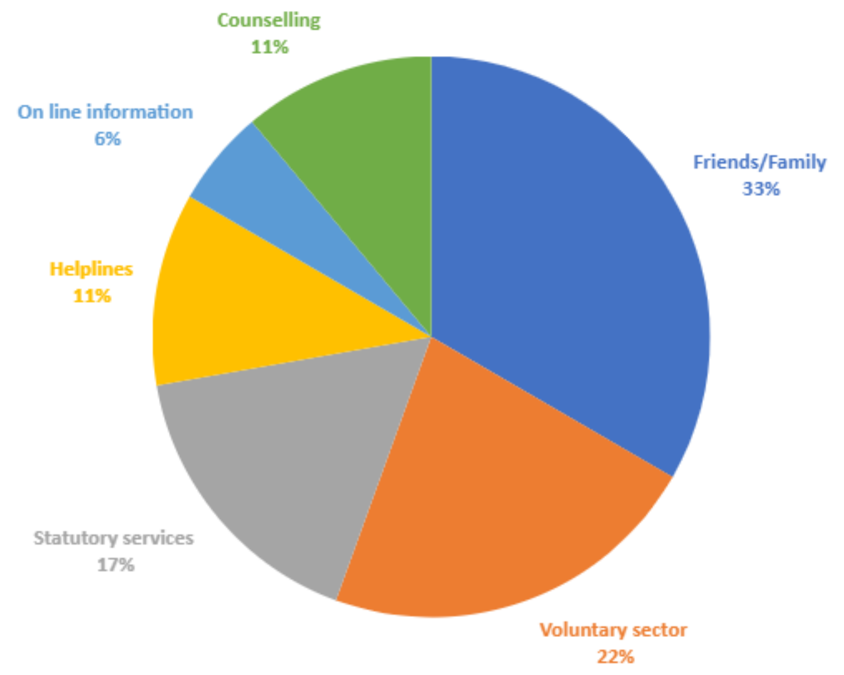
Findings from survey on key issues

1.Challenges (multiple choice answer options)

40% of participants cited acceptance, frustration, and feelings of being trapped as the biggest emotional challenges they faced.

30% listed that they experienced tiredness and depression and 20% mentioned fears for the future and guilt. They stated their self-confidence was diminished.

2. Assistance (single choice answer option)



33% said their need for help was predominantly answered by family and friends. 22% of the cohort also cited voluntary organisations, memory cafes and talking to other Carers. Statutory organisations support was indicated as helpful by 18% of our group. Telephone support was mentioned (11%), along with online courses (11%) and counselling (5%).

3. Peer support (multiple choice answer options)

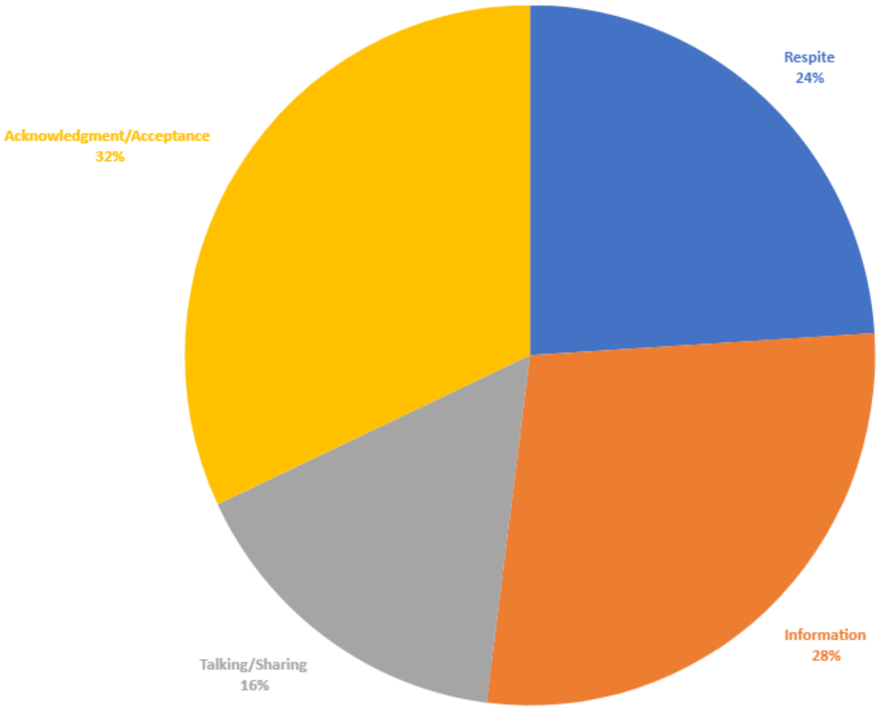
Peer support was favoured by 90% of the group with the preference for this being face-to-face at voluntary sites and 40% said they would like additional telephone support, befriending by other dementia Carers (40%). Shared leisure activities were enjoyed by 30%.

4.Stages where support is most needed (multiple choice answer options)

The entire group agreed support is essential after diagnosis, but some (40%) said it needed to be staggered or delayed as this was overwhelming. Support was indicated as needed during major care or medication change (30%), when giving up work and taking on full-time care (40%) and if hospitalisation was required (20% -

although only a subset experienced this). 20% stated they felt that extra support during heavy appointment schedules in the initial stages, would help.

5. Essential ongoing needs (single choice answer option)



24% cited respite in either day or short break packages, information was seen as essential by 28%, opportunities to offload was expressed as necessary by 16%, acknowledgement of the role was of primary importance at32%.

In their own words

"I won't ask for help until I really need it. I am struggling at times, but I don't want them to think I can't cope and take him away from me or put him in a home. I can manage, it's just sometimes I get so tired, and it would be nice to talk to someone … someone who wouldn't judge and that." **- A. (58) - caring for husband.**

"We were not offered support for us. We don't really know of any. The Chinese group did find us Chinese speaking domestic help which was good but we couldn't find any Chinese speaking care support which would have helped my father as his English wasn't good. It's something that would be useful, Carers (who can care) in the persons own language." - **C. (64) caring for father.**

"You have concerns about getting into the system. You feel unable to ask for what you need because of the stigma." - **focus group**.

"It was hard to watch someone deteriorate, not get better with your care but worse - it's very emotional. I found it depressing" **- M. caring for father-in-law.**

"There is not enough representation within the services for all groups. More staff volunteers, and people accessing services that represent all diverse groups in society. (build a varied team)- so then you encourage all groups to access and use services." **- focus group.**

"People assume that you can cope because you are cheerful, they assume things are ok and that you are managing when often there is a lot going on and you are not coping and can hardly manage daily stuff like clearing up." - **P. (65) caring for wife.**

"I don't need help but when I can get some respite I just want to talk" - ***A. (58) caring for husband.***

"The day she died it was, and it's horrible to admit, a huge relief...finally I could grieve for my mum as she had been, rather than what had happened in those last years." - ***S. (50) cared for her mother.***

"I felt I was being told at 50 that life was over – but I have discovered that it is possible (for her) to live fairly well with dementia. At first, I struggled with the idea – I wanted it to be something you could get rid of – but while you can slow the affects you can't change the progression – it is a terminal diagnosis." - **T. caring for wife.**

"It's confusing, there are a lot of marvellous resources, but they are not very joined up and it depends so much on where you live, as to the service you are offered." - **P. (65) caring for wife.**

"I need someone to talk to 24/7, who would take time and listen, in the middle of the night when he is asleep, and I need to talk about how bad I feel sometimes when he ignores me or forgets things." - **O. caring for husband.**

"My advice for anyone starting to live with dementia would be to join a support group. Laughing, crying, and screaming with other people – sharing experiences and not being alone – and leaving it all in the room!" - **T. caring for wife.**

"GPs often tell the wrong story, as they describe dementia as an integral part of aging but there are multiple forms of dementia, it can happen to anyone, and not only the elderly. People need to understand and differentiate the different forms of dementia." - **T. caring for his wife.**

"As someone who is more able, younger, it's easier for me to be mobile and out and about – harder for those who are 70 rather than 60." - **C. caring for husband.**

"Of course, every caring situation is unique, there may be similar issues, but some people will find talking face-to-face helpful and others would prefer the internet." - **M. Carer.**

"He follows me, I am in the house and he follows me around or doing the garden, he just follows me - it is draining." - H. **caring for husband.**

"Once in the system it tends to carry you along, which is good but also feels like a loss of control, so much to do, so many appointments" - **J. (59) caring for husband.**

"It's important that you feel like you still have a role rather than sitting here waiting for things to happen."- **M. caring for wife.**

"I felt so so sorry for my husband. We had no time to do anything else, too tired anyway. I would have liked to talk to someone else, not necessarily Chinese but just someone going through the same thing, to share some thoughts and experiences with someone who knew what we were going through." - **M. caring for father-in-law.**

"The beginning was slow and insidious, it was in the back of my mind, but we were both in denial. I didn't realise how bad it had become, he hid it from me too, he was a very proud man, we began to have confrontation." - **J. (59) caring for husband.**

"There are new things we could do together as we made a whole new set of friends and things to do, and we met two couples – and now go for lunches and National Trust." - **C. caring for husband.**

"I accepted the caring and responsibility, but it was tough, he became forgetful and needed help but it's part of getting older and I was able to accept that."- **C. (64) cared for his father.**

"I have less friends now. A core group who understands ...and I rely on their support. Isolation is so hard; people are essential." - **J. (59) caring for husband.**

Outcomes

In response to the feedback collected from Professionals and Carers, Healthwatch Bristol and Healthwatch South Gloucestershire created a local user-friendly resource called '*Dementia Carers Support Map'* to accompany this report. It is designed to assist Carers and the Professionals who advise them. The online resource incorporates the requests and suggestions that we received as part of the co-design section and the later narrative data collected from lived experience participants.

Click here to view the online support map

Or type https://sites.google.com/view/hwb-hwsg-dcsm/home into your search engine

For those who prefer a summary list of the key resources that appear in the '*Dementia Carers Support Map'* can be found in Appendix 3

Recommendations

We believe the following recommendations to be achievable, affordable and evidence based:

- There should be the development of a free accessible befriending service to include peer support, telephone, and face-to-face communication.
- Carer focused appointments are offered flexibly to meet their needs.
- The Caring persons' emotional wellbeing becomes part of the initial consultation and continues throughout the caring journey. (Ideally use 'Triangle of Care' (Ref 5) model to facilitate the involvement of Carers).
- Make community level counselling available to all Carers of people with dementia across a minimum of six sessions and offer respite to enhance their wellbeing.
- Where English is not the first language of patient and/or Carer, services must find ways to provide culturally sensitive & appropriate care and support.
- Provide a single point of information that has digital and physical availability.
- Guides to the specific journey of a dementia Carer are made relevant to different cultures and ages.
- The community resource directory is updated regularly.
- The *Dementia Carers Support Map* becomes a recommended resource used by professionals and valued by Carers in the Bristol and South Gloucestershire areas.

Appendix 1

Co- design partners

Alzheimer's Society –Bristol Dementia wellbeing service - https://www.bristoldementiawellbeing.org/

BDAA - https://www.bdaa.org.uk/

Bristol Mind - http://bristolmind.org.uk/

Carers Support Centre - https://www.Carerssupportcentre.org.uk/

Rethink - https://www.rethink.org/

Appendix 2

Stakeholder Responses:

“This is so insightful and it's great to see it all pulled together for identifying and supporting carers' needs.'” - Dr Julie Clayton, Public & Patient Involvement and Engagement, Bristol University and Project Manager for the Dementia Health Integration Team, Bristol Health Partners

“'(Its) something I hear a lot that people (say, they) just don’t know where to start to look for information when they set out on the dementia journey so a one-stop shop, such as this map, to me seems useful and looks comprehensive.” – Project Stakeholder

Appendix 3

Resources identified which have formed the basis of the online map:

Diagnosis

Dementia information

How to get a dementia diagnosis, NHS
https://www.nhs.uk/conditions/dementia/diagnosis/
Early stages https://www.alzheimers.org.uk/about-dementia/symptoms-and-diagnosis/how-dementia-progresses/early-stages-dementia

Psychological support

South Gloucestershire's Talking Therapies you could refer yourself directly to the Wellbeing Service. Their practitioners can help you find ways of talking or coping with your problems. Phone: 0117 378 4270
Help for new Carers **https://www.Carerssupportcentre.org.uk/**

Finance and day to day care

Power of attorney https://www.alzheimers.org.uk/get-support/legal-financial/lasting-power-attorney
Advance decisions https://www.alzheimers.org.uk/get-support/legal-financial/dementia-advance-decisions-statements
SG guide to services https://www.southglos.gov.uk/documents/Dementia-Guide-to-Services-in-South-Gloucestershire.pdf

Medication and care changes

Explanations why and what next

Understanding dementia medication https://www.alzheimersresearchuk.org/dementia-information/types-of-dementia/alzheimers-disease/treatments?gclid=EAIaIQobChMIm_mP96H77wIVCM93Ch2-fAZZEAAYASABEgJ_kfD_BwE

How do I access help?

Wellbeing service https://bristoldementiawellbeing.org/Use-our-service/Contact-Us including translations and cafes.

Giving up work

Need for emotional support.

Carers psychological support https://bristolmind.org.uk/support_type/Carers-support/

Need to stay social.

Example https://www.facebook.com/happydaysmemorycafe/

Financial worries

Support and allowances https://www.independentage.org/get-advice/support-care/support-for-Carers?gclid=EAIaIQobChMIkNj_waP77wIVhuh3Ch280wqeEAAYASAAEgIOdPD_BwE

Hospitalisation/care home

Loneliness

Safe environment, peer support https://www.alzheimers.org.uk/get-support/your-support-services/peer-support

Visiting as a Carer

Visiting as a Carer https://www.scie.org.uk/dementia/Carers-of-people-with-dementia/supporting-Carers/hospital-and-care-homes.asp

Bereavement

Counselling

Bristol https://the-harbour.org.uk/counselling/
SG https://edocs.southglos.gov.uk/bereavementguide/pages/support-for-Carers-and-anyone-in-south-gloucestershire-who-has-lost-someone-close-to-them/

Peer support

Create your own? https://www.voscur.org/calendar/event/setting-your-own-bereavement-peer-support-group-bristol
Signpost to local via https://www.cruse.org.uk/

Dementia specific

Grief and loss https://www.dementiauk.org/get-support/looking-after-yourself-as-a-Carer/bereavement/

References

1. Living well with dementia in Bristol. A joint commissioning strategy.2011-2015. NHS Bristol & Bristol City Council Health & Social care.

2. JSNA 2020 health and wellbeing report 2019 https://www.bristol.gov.uk/documents/20182/3849453/JSNA+2019+-+10.1+Dementia+-+FINALv2.pdf/88d89dbf-7da4-aacb-39f9-b787e4034b70 and https://edocs.southglos.gov.uk/jsna2017/pages/adults/dementia/

3. Projections of older people with dementia and costs of dementia care in the United Kingdom, 2019–2040.The London School of Economics & Political Science. Raphael Wittenberg, Bo Hu, Luis Barraza-Araiza, Amritpal Rehill. Nov.2019

4. Carers Support Centre, Bristol & South Gloucestershire https://www.Carerssupportcentre.org.uk/news/facts-about-caring/

5. Carers Trust (2013) The Triangle of Care, Carers Included: A Guide to Best Practice in Mental Health Care in England. Second Edition

Acknowledgements

With thanks to:

ADAPT Project (UWE), Alzheimer's Society, Bristol Dementia Wellbeing Service, BRACE, Bristol & Avon Chinese Women's' Group, Bristol City Council, Bristol Dementia Action Alliance, Bristol Mind, Carers Support Centre, Sirona Care and Health, UHBW, Vitaminds, West of England Care & Repair, Carers Support Centre, our Healthwatch volunteers Grace Spencer, Roxana Seifer, Megan Tyler & Karen Whitaker

Cover photograph by Tetiana SHYSHKINA on Unsplash

Special thanks to those caring who spoke to us with such honesty and emotion.

Healthwatch Bristol, North Somerset and South Gloucestershire
3rd Floor The Sion
Crown Glass Place
Nailsea BS48 1RB

contact@healthwatchbristol.co.uk contact@healthwatchsouthglos.co.uk

www.healthwatchbristol.co.uk www.healthwatchsouthglos.co.uk

Accessibility: If you require this document in another format, please let us know.

Date May 2021