

It's all about the break!

2015

Public Social Partnership

Authorship Statement

This research report is based on the results of the “It’s all about the Break!” consultation carried out by myself and is my own composition. The research was carried out under the supervision of Lucinda Godfrey and the Dundee Public Social Partnership.

Acknowledgements:

Thanks to everyone who has contributed to the consultation. In particular, I would like to acknowledge everyone who participated by giving their time and sharing their views.

Contents

Introduction and background.....	3
Methodology.....	5
Findings and Discussion and Analysis.....	7
Conclusions and Recommendations.....	27
Appendix 1.....	37
Appendix 2.....	44

IT'S ALL ABOUT THE BREAK!

RATIONALE

A Public Social Partnership (PSP) has been developed in Dundee including representatives from the third sector, Dundee City Council Social Work Department and NHS Tayside. The aim of the PSP is to explore, design and test a new models of Short Break supports for unpaid carers of people with mental health support needs, who use Mental Health Services by exploring the best ways to provide respite.

INTRODUCTION AND BACKGROUND

Lynsey McCallum (Mental Health Service User Involvement Co-ordinator) took a leading role with the support of the PSP to garner involvement from carers who have a substantial caring role for someone with mental health support needs and also service user involvement from the mental health service user population in Dundee. The PSP were looking for people to share their views about the need for short break supports and what that might look like.

McCallum, with the input of the PSP devised a set of questions they wished to put to the mental health carer and service user population, to consult on their views and experience around short breaks provision. The focus group guidance and questionnaire went through a process of being checked over for validity and quality assurance and signed off by the PSP project and governance groups before the data gathering phase began.

The PSP has been committed to using co-productive approaches which has put carers and supported people at the centre of service design and delivery and will ultimately involve them in every aspect of the process – identifying need, designing actions, sharing in delivery, monitoring and evaluating.

INCLUSION CRITERIA FOR PARTICIPATION IN CONSULTATION

The inclusion criteria for participating in the consultation was not quite as specific as the criteria for accessing a break. Throughout the consultation process, the PSP were looking for involvement from adults, over the age of 16 years, who live in Dundee, and have an unpaid caring role for someone with mental health needs or have lived experience of mental health difficulties and accessing services. The PSP believed that including the opinions and experience of people who had lived experience, but did not clearly meet the criteria for accessing a break was of equal importance. By means of giving local people an opportunity to be involved as partners in shaping service delivery in Dundee. Thus resulting in a model of Short Breaks with better outcomes. On these grounds, people who did not clearly meet the

criteria for accessing a break were not excluded from participating in the consultation. However, it was made clear to all respondents that by taking part in the consultation, did not mean you are automatically eligible for a break (see appendix 1 ‘front cover of questionnaire’).

Nevertheless, there is a need to have an eligibility criteria for accessing a short break from the pilot, due to a limited amount of funding available for this test of change. The criteria for accessing a break are; the person accessing a break must be an adult (16 years +), must have an unpaid carer who has a substantial and regular caring role and would benefit from the short break/respite (this does not mean the carer has to live in the same household as ‘cared for/supported person’), must be open to the Community Mental Health Team – either from a Social Work or Health perspective (doesn’t need to be both) and must not live in a commissioned supported living service where the care and support is provided by a paid carer.

PARTICIPANTS

During the “It’s all about the break” consultation, a total of 60 individuals were engaged. The respondents comprised of unpaid carers, cared for people and service users, who shared their opinions and experience. There were a variety of recruitment methods used to try and encapsulate as representative a sample as possible.

The following methods were used with a breakdown of individuals engaging with said methods:

Method	Number of participants / respondents	
Focus Group x 4	30	
Individual Interviews (This was due to not enough people attending a planned focus group)	1	
Questionnaires *(distributed in outreach and drop in sessions and also with service providers involved in the PSP)**	29	<u>Total questionnaires completed:</u> 29
Web based questionnaire (advertised through DVA website, Dundee SUN facebook page and Dundee Carers Centre)	0	Identifier: Service User – 23 Cared for person – 6 Unpaid Carer – 4 I am/have unpaid carer and also have support provided – 8***
Total amount of participants	60	

* Please see appendix 1 for the questionnaire that was used. Comment boxes were added after some of the questions to try and further explore people's views.

** Outreach/Drop In visits – Dundee Association for Mental Health (10), Dundonald Day Centre (5), Hearing Voices Network (2), Dundee S.U.N Drop-In (3) and Cairn Fowk carers group (4).

***Please note service users and cared for persons are referred to as one group throughout this report as some people ticked more than one identifying box in the questionnaire. Everyone who ticked the cared for person box also identified themselves as a service user. This is why service user and cared for persons are referred to as one group.

Providers involved in the PSP also contributed some completed questionnaires from the people they are supporting. These are as follows; Penumbra (2), Richmond Fellowship Trust (2) and Dundee Carers Centre (1).

Other Mental Health Services (SAMH, Art Angel and Dramatherapy) had made the consultation process known to their client group but did not identify individuals either applicable to this process and/or willing to engage.

METHODOLOGY

The research strategy that was selected as most appropriate to underpin the 'It's all about the break' consultation, is the action research strategy. More recently, action research has been used in a variety of settings within the social sciences, but its growing popularity as a research approach perhaps owes most of its use in areas such as; health and social care, education and organizational development. In these areas it has a particular niche among professionals using research, to improve practice. Research should not only be used to gain a better understanding of the problems which arise in everyday practice, but eventually set out to effect change. Change as part of the research process, as opposed to tagging it on completion of the research, as an afterthought. Highlighting another defining characteristic of action research – its commitment to a research process in which the application of findings and an evaluation of their impact on practice as an integral component of the research cycle. Furthermore, involving those affected by the research in the design and implementation of it, encourages participation as collaborators in the research rather than being the subject of it (Densombe, 2007). The action research strategy was also adopted as most appropriate because it is concerned with the aims and design of the research. This strategy does not specify any constraints with reference to the methodology that may be adopted by the researcher, lending itself to the use of different techniques for data collection (Dencombe, 2007). The participatory nature of action research is probably its most distinctive and appealing feature in terms of this research. Involving people throughout the consultation

process, encourages active participation and partnership working. This includes; design of the consultation, the co-production of the pilot, the evaluation of the whole process and finally evaluating the experience of having a break is of paramount importance for the PSP.

The research methods used in the consultation are; questionnaires, face to face interviews in the form of focus groups and also web based questionnaire on host sites (see table in participants section).

Probability sampling has been used (refer back to participation criteria) and as the name suggests, it is based on the notion that participants are chosen as the sample. This is because the researcher has some idea of the probability that there will be a representative cross section of people or events in the whole population being studied (Descombe, 2007).

Inductive research design and reasoning was applied to the consultation, which involves drawing a general conclusion or principle from specific examples through a logical process of induction (the opposite of deduction) (Wisker, 2009). Inductive logic is carried out by growing or developing a theory based on data collected on people's feelings and views, produced from the results of, in this instance, focus groups and questionnaires (Wisker, 2009).

Questionnaires, focus groups and one individual discussion, were guided by the questions set and agreed by the PSP project and governance groups. Please see appendix 2 for focus group questions. Points were then transcribed from each question.

Questionnaire feedback has been reported back in a descriptive manner and also in tick box format displayed in tables. Any key supporting points written as comments on the questionnaires have been reported as they were written by respondents.

Feedback and discussions have been amalgamated into key themes. The themes have been identified through repetition. Key supporting points and descriptive analysis have been reported verbatim, in the Findings, Discussion and Analysis section of the report.

FINDINGS, DISCUSSION AND ANALYSIS

The various key themes that have emerged in response to questions asked in the questionnaires and focus groups are distinguished by the response from unpaid carers and also service users and cared for persons. The feedback is located under said headings throughout the report. The findings from the data collected during the consultation are displayed and discussed under four main sub headings. The four sub headings are:

- What do you want from a break?
- What do you want a break to look like?
- What do you feel might get in the way?
- How is it going to work?

Q.1 – Have you ever had a short break?

Table 1 includes all consultation respondents, including those who completed a questionnaire and also those who took part in a focus group. The aim of table 1 is to provide an overview of how many respondents had previously accessed a break.

Table 1

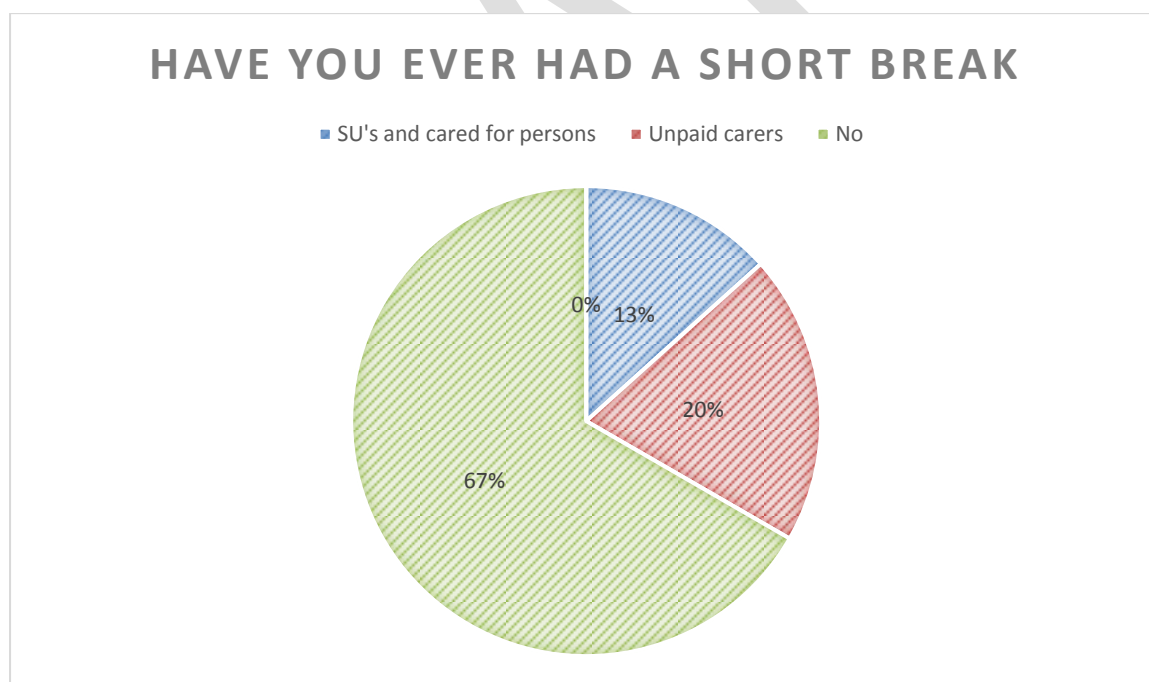


Table 1 illustrates quantitative data: Of the total amount of consultation respondents 33% had previously accesses a break. The 33 % was comprised of 13% of service users and cared for persons having accesses a break and 20% of unpaid carers having accessed a break. The majority of respondents 67% had not previously accessed a break. The percentages in the pie chart equate to eight service users and cared for persons and twelve carers having had a break previously.

WHAT DO YOU WANT FROM A BREAK?

The following key themes have been constructed from qualitative data gathered from an amalgamation of both the questionnaires and focus groups in response to the question below. The question below was asked in both the questionnaire and focus groups. The qualitative feedback is displayed in figures 2 – 2.7.

UNPAID CARERS

Q.7 – How should a break benefit you?

Key theme 1: Improved Health and Wellbeing

Figure 2

<i>“To get away from the stress you are going through”</i>
<i>“It should be stimulating in some way, be different from the daily routine and leave me refreshed and better able to cope afterwards”</i>
<i>“Takes you away from day to day life, not worrying about cooking and cleaning etc”</i>
<i>“To have no worries or cares for a few days and just enjoy the freedom”</i>
<i>“We really need this, not having a break can run you into the ground”</i>
<i>“Helping us to have a break can enhance our health”</i>
<i>“Having a break definitely promotes wellbeing”</i>
<i>“Helps to relax and carer to feel positive in role”</i>
<i>“Helps you to carry on with caring”</i>
<i>“Activities can be therapeutic, I actually managed to concentrate to take part in activities”</i>

Key theme 2: Having a break with other carers is helpful

Figure 2.1

<i>“I enjoyed the company of other people in the same boat as me”</i>
<i>“Sharing information about services available is helpful”</i>
<i>“You hear other people’s stories and can identify with them”</i>
<i>“You get a lot of support from other carers”</i>

“It’s something you wouldn’t do on your own”

Key theme 3: A break away from the person I care for is helpful

Figure 2.2

“Getting away from my husband and getting help to get a break”

“I would get away from the day to day life and routine as a carer”

“It should give me a break while knowing that my partner is being cared for”

“Helps you to re-charge the batteries and go back in a better frame of mind to my caring role”

“I learned how to relax, there’s a big difference in me when I’m away from my caring role”

SERVICE USERS AND CARED FOR PERSONS

Key theme 4: Improved Health and Wellbeing

Figure 2.3

“It should benefit my overall wellbeing”

“Lets you put things into perspective. It should be enjoyable. It definitely improves my wellbeing”

“To improve interpersonal skills, wellbeing and insight”

“Improved health, wellbeing and movement”

“I should be relaxed and better able to cope with daily stresses after having a break”

“It would help my mood, plus be able to cope much better when I get home”

“Something that would free my mind from my chaotic thoughts”

“When I go away my OCD symptoms reduce, not intensify”

“Get away from the home environment. OCD is worse when you’re in your own environment”

Key theme 5: A change of scenery and routine

Figure 2.4

<i>"I need a change of scenery to escape from my life and distress"</i>
<i>"Getting away from my normal days. It would hopefully be peaceful and free my mind"</i>
<i>"A break away from Dundee"</i>
<i>"Change of scenery and break of routine"</i>
<i>"A change of scenery, chill out time"</i>
<i>"Get me away for a few days. A change of scenery"</i>

Key theme 6: Try something new

Figure 2.5

<i>"Try new things and get involved with new people. It is the next step in recovery for lots of people"</i>
<i>"Positive experience – There are things I want to do before I am physically unable"</i>
<i>"Meet new people, see new places"</i>
<i>"A different environment and change of scenery, it can help build my confidence"</i>

Key theme 7: Relaxation

Figure 2.6

<i>"Peace, quiet and relaxation"</i>
<i>"Just to relax"</i>
<i>"It should be relaxing"</i>
<i>"It would give me a rest somewhere peaceful"</i>
<i>"I feel the journey would be good for me, I feel relaxed when I am travelling"</i>

Key theme 8: Carers may benefit from a break

Figure 2.7

“My carer may benefit from me going away, she would get a break from supporting me”

“Both carer and cared for need a break sometimes”

“Carer can benefit from a break from caring, but they would also benefit from a break together”

There were some similarities in the key themes that emerged from both the carers and cared for in response to the question. For example, figure 2 and figure 2.3 demonstrates the fact that carers and cared for identified a break as helping them to achieve improved health and wellbeing and hoped to be ‘feeling more able to cope’ after a break. Another similarity identified by both carers and cared for, is that carers will benefit from a break from their caring role. This notion is highlighted in figures 2.2 and 2.7 and could involve the carer going on a break or the cared for going on the break and the carer benefiting as a by-product. A small number of cared for felt that the carer and cared for may benefit from a break together. However, the latter point is in contrast to the majority of responses from carers. Almost all carers who shared their views said that they would benefit from a break without the cared for person. Only one carer said that they would benefit from a break together. The person they care for is their child and as it is the norm to care for a child they felt less need to have a break away from their caring role, preferring to go on a break as a family.

A significant number of carers said that getting away with other carers had benefits that they found helpful, such as mutual support, being with people ‘in the same boat as me’, and feeling like they can identify with each other, all of which is beneficial to carers.

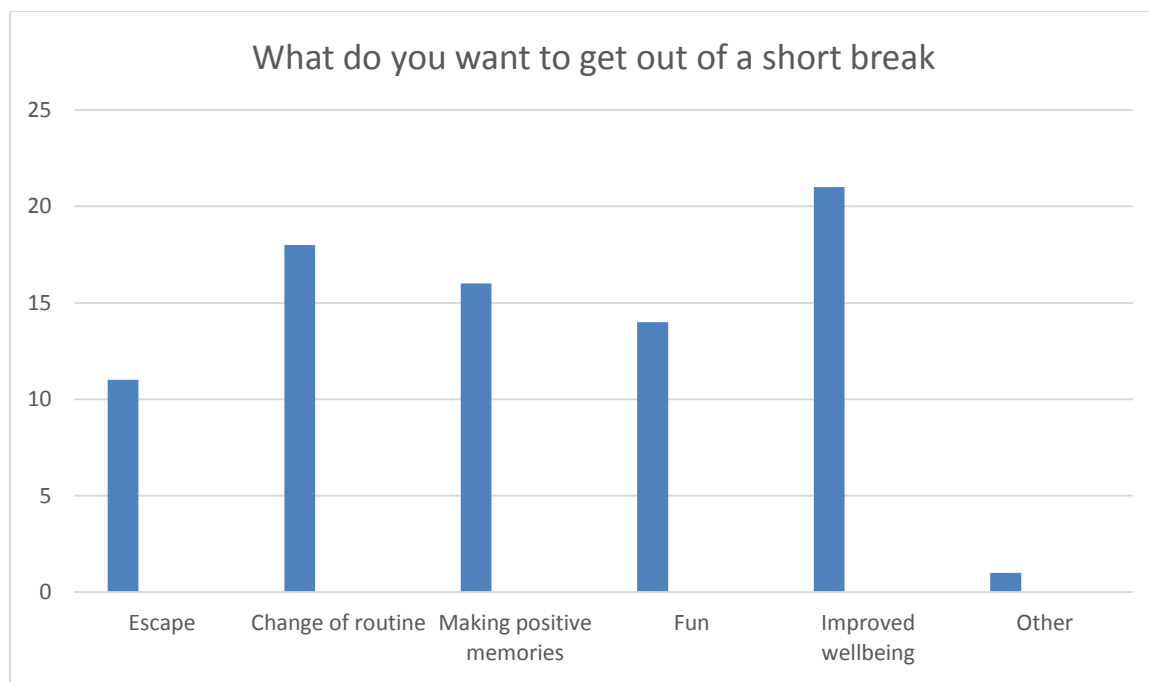
Cared for identified some additional benefits. A change of scenery and routine emerged as a theme that was important, coupled with the positive effect that having a break from their routine or ‘normal days’ could have on their mental wellbeing. In figure 2.4 one person noted a break may help them to “escape from my life and distress” and another said it would “free my mind”. Relaxation was another benefit that was identified from having a break, as well as trying something new. It was suggested in figure 2.5 that having a break can be the ‘next step in recovery for lots of people’ by meeting new people and trying new things which can help boost an individual’s confidence by exposure to new places and people.

Q.16 – What do you want to get out of a short break?

Questionnaire

Table 3 below includes feedback from all questionnaires completed by respondents.

Table 3



When asked, what do you want to get out of a short break? The most popular choice was 'Improved wellbeing', followed by 'change of routine'. 'Making positive' memories was the third most popular choice selected by participants thereafter, which was closely followed by fun. This feedback is also in keeping with the key themes which emerged in the focus group feedback to the same question - how should a break benefit you? Improved health and wellbeing and change of routine were also identified, which suggests that there are strong and valid key themes.

WHAT DO YOU WANT A BREAK TO LOOK LIKE?

Table 4 below includes feedback from all respondents in the questionnaire and focus groups.

Q.11 – Preferred method of selecting a break?

Table 4

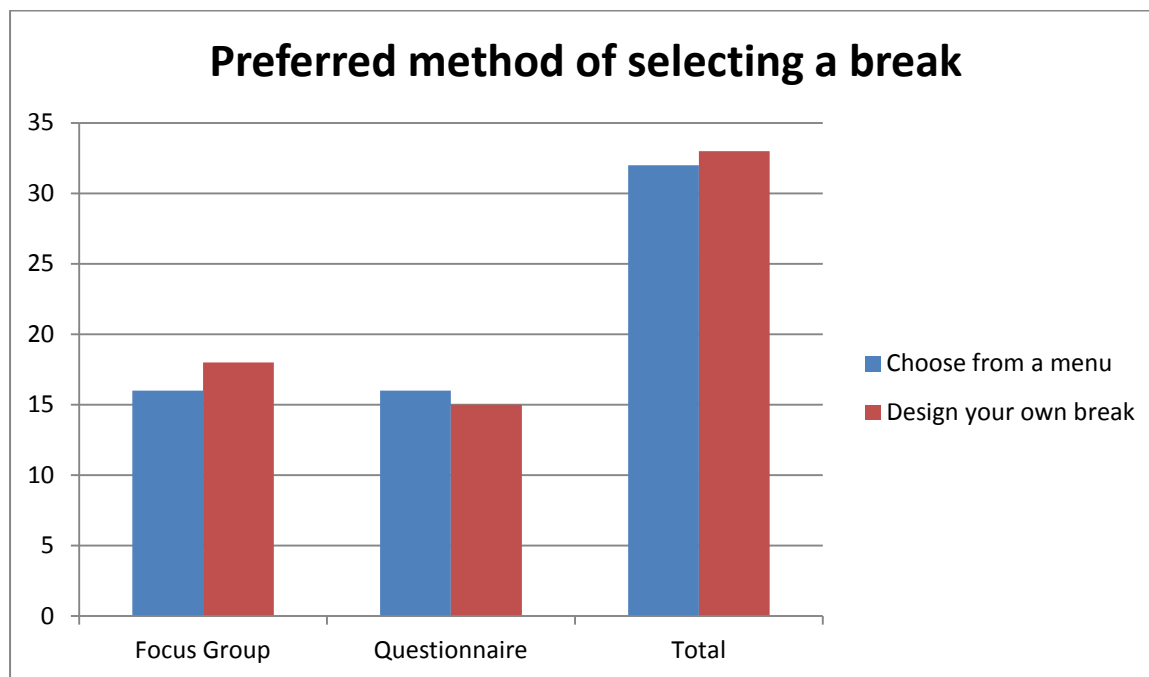


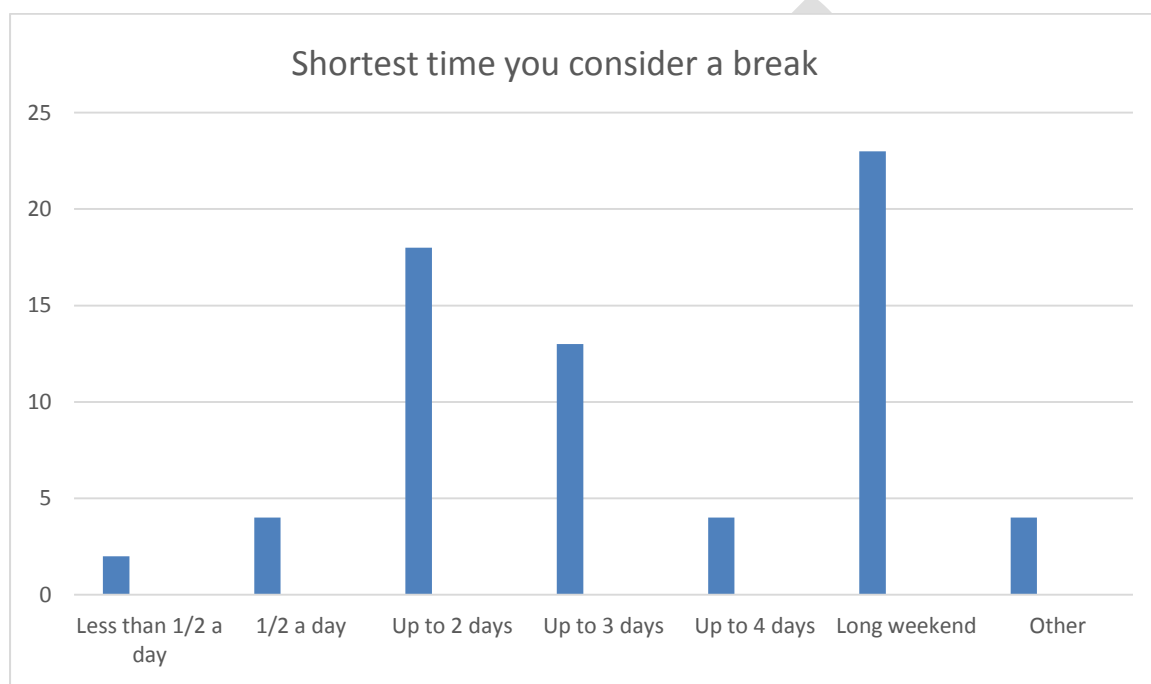
Table 4 illustrates the number of respondents in the questionnaires and focus groups who selected their preference of choosing a break from a pre-set menu or designing your own break. Thirty two respondents selected 'choose from a menu' and thirty three respondents selected 'design my own break', which was ultimately the most popular choice.

Please note that the total number of respondents totals more than 60 participants overall. Though the question stated please tick one box, two respondents in the questionnaire ticked both boxes and three participants in the focus group selected both options. In the questionnaire, one respondent who selected design my own break also added "I would be open to looking at a menu".

Q.9 – What is the shortest time you consider a break to be?

Table 5 Includes responses from all participants in the questionnaires and focus groups amalgamated into one table. This provides an overview of the shortest time respondents considered a break to be.

Table 5

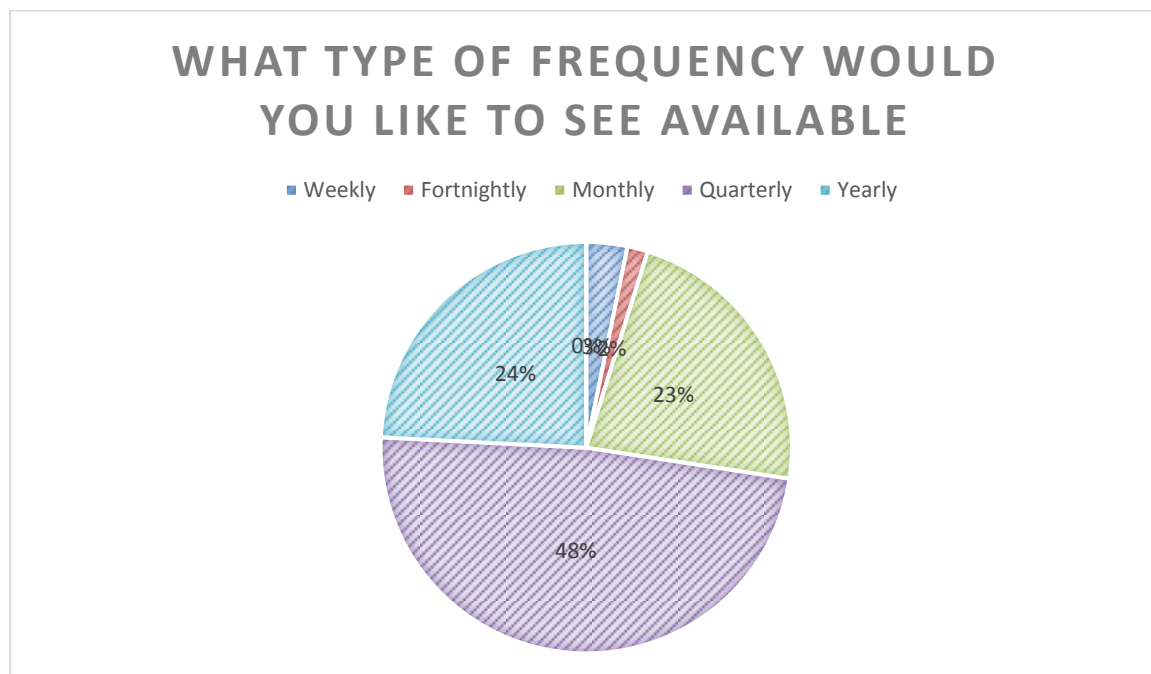


By far, the most popular answer for the shortest time you consider a break is a long weekend, with twenty three respondents selecting this choice. This was followed by 'up to 2 days' with eighteen respondents selecting this option and then 'up to 3 days' with thirteen respondents opting for this. A point to note is that all four participants who selected 'other' identified the shortest period of time they consider a break is 'one week'.

Q.10 – What type of frequency would you like to see available?

The pie chart below includes all feedback, including questionnaire and focus group responses to the question below of frequency.

Table 6



In terms of frequency, the most popular choice is quarterly with 48% of participants selecting this. This may be indicative that participants may want to have the ability to have a subsidised break more than once a year. The second most popular choice is yearly with 24% of participants choosing this option. Followed very closely by monthly with 23% of participants choosing this option. There was only 1% difference between yearly and monthly. Weekly and fortnightly were not popular choices among respondents.

WHAT DO YOU FEEL MIGHT GET IN THE WAY?

Q. 18 – What would make it difficult for you to have a break?

Questionnaire

Table 7 is set out similarly to question 18 in the questionnaire. Respondents were asked to tick three which apply to you and rank them in order of importance.

Table 7

Potential Barriers	Service User	I have an unpaid carer and support	Unpaid carer	Total
Medical Issues	13		2	15
Meal provision	5		1	6
Responsibilities/commitments	2	1	2	5
Appropriate accommodation	6		2	8
Adequate support	10	2		12
Transport	6	1	2	9
Accessible toilets	6	1		7
Unsure how to access services	11	1	1	13
Cultural needs				0
Mobility	5		2	7
Cost	2			2
Other	Single room			1

Table 7 illustrates a broad range of personal barriers identified by the respondents. The top three potential barriers for accessing a break are; ‘medical issues’, ‘unsure how to access services’ and ‘adequate support’. One respondent added a barrier in an additional comments box stating ‘single room’. Furthermore, cultural needs, was not selected by anyone as a potential barrier. It is important to note that Black and Minority Ethnic (BME) communities were not effectively represented as part of the overall research sample. There were only two respondents who didn’t use English as their first language. Perhaps, if there had been BME representation we may have saw cultural needs as a more prominent potential barrier.

The same question was also asked in the focus groups and key themes have been generated based on the respondent's answers.

Q. 18 – What would make it difficult for you to have a break?

Focus Groups

UNPAID CARERS

Figure 7.1

Key theme 1: Cost – Many carers said that their 'finances' or 'cost' could be a barrier to accessing a break. One carer who has previously accessed a break for herself and her son on two occasions said that *"funded trips made it possible otherwise this would be difficult"*.

Figure 7.2

Key theme 2: Adequate support in place for cared for person – A significant amount of carers identified that it was of paramount importance to have *"the right kind of support in place for the cared for person"* and the comfort of *"knowing that everything is in place for the cared for person before I go on the break"*. If the right kind of support is not in place, it became apparent this would impact how the carer feels about accessing a break, and also their ability to fully enjoy the break and reap the benefit of this without worrying about their loved one at home.

Figure 7.3

Key theme 3: Dietary requirements – A small number of carers identified dietary requirements as a potential barrier. This included the need for decent vegetarian and gluten free meal options to be readily available. Furthermore, this also included difficulties such as celiac disease to be catered for.

Figure 7.4

Key theme 4: Accommodation – Accommodation was a feature of the discussion with carers. It was noted that *"Sharing a room can sometimes be difficult but I still like going away as a group"* another carer went on to add *"If it's a place that has bunk beds, someone has to go on top, that's not always easy, especially if you're a bit older"*. There was consensus among the other carers about these points. However, all of the carers did agree that sharing a room with bunk beds would not completely deter them from taking up a break where this type of accommodation and sleeping arrangements were on offer.

Figure 7.5

Key theme 5: Relationship strain – Many carers said that they feel guilty for needing a break or are “*made to feel guilty for needing a break*” by the person they care for. This notion was echoed by several carers during the focus group. A carer went on to say “*the cared for persons mood*” is a factor and another said that a barrier can be “*the behaviours of the cared for person, my daughter kicked off before the last break I had, but I made the decision I was going regardless as I really needed a break*”. Other carers went on to acknowledge they have had similar experiences like this and that she was not alone with this experience.

Figure 7.6

Key theme 6: Health problems – Health problems were a feature of discussions with carers. This included the health problems of the cared for person, if they were well enough mentally and physically to access a break with their carer or for the carer to feel comfortable about going on a break without the cared for person due to their frame of mind. A carer also identified “*your own health problems, sometimes I have poor health*”. A number of carers also agreed with this comment as they also experience their own health problems.

SERVICE USERS AND CARED FOR PERSONS

Figure 7.7

Key theme 7: Cost – A significant amount of service users and cared for people expressed cost as a barrier to accessing a break. This is a strong theme and was a feature of the discussion in each of the focus groups held with the service user and cared for person’s population.

Figure 7.8

Key theme 8: Responsibilities / commitments – Many participants said that responsibilities and commitments may hinder their availability to have a break. A smaller number of participants went on to say this included having children and pets which would need to be looked after to allow them to access a break, unless children and pets could also be accommodated on the break. This also included work and college commitments and the need for a break to fit in with annual leave entitlement and academic term holidays.

Figure 7.9

Key theme 9: Adequate support (the right person to go with me on a break) – A significant amount of service users and cared for persons identified that they would need support in place from the right person, “someone I trust”, in order to feel confident enough to go on a break. “*Who is to accompany me on a break*” was an important consideration to many. Some of the comments made included; “*I get*

nervous travelling alone, I would need someone with me for support". Participants identified that they may feel *"Out of my comfort zone"* and that in order to cope with this I would need to feel *"That I am properly supported"*. Though a break would be a great experience and of real benefit for individuals, accessing a break *"would push the boundaries"* for many people, albeit in a positive way. Knowing that adequate and responsive support was in place if needed was important to service users and cared for persons in the event of becoming unwell or some type of crisis developing while away.

Figure 7.10

Key theme 10: Medical Issues – A significant number of participants said that 'my symptoms' or condition could be a potential barrier to having a break. Many people said that how they feel on a day to day basis can be quite unpredictable and having a 'down spell' could make having a break difficult. Mood swings, anxiety, paranoia and trust issues were a common feature in the focus group discussions - which also appeared to link with people's fear or dislike of overly crowded places, enclosed spaces and fears around meeting and trusting new people.

Medical issues was also a prominent feature of the discussions in the focus groups. This encapsulated a number of reasons and examples, such as *"people around me knowing how to handle blackouts"*. Medication was also an important point to note, for example, *"having medication all organised as some people need to collect this regularly"* and *"I would need enough medication with me, which would require planning"*. Medication resonated as an important concern within many of the focus groups.

Figure 7.11

Key theme 11: Safety 'feeling safe' / back up plan – Several participants noted that safety - "being and feeling safe" is of paramount importance when going on a break. This point was mentioned in each of the three focus groups held with service users and cared for persons. One gentleman who had previously went on a short break said on arrival *"I was made to feel welcome and safe"* which he said put his mind at ease and set him up for having an enjoyable time. It was also identified that having a 'backup plan' ready in case someone becomes unwell is vital. Service users and cared for persons felt they need the assurance that everything will managed well in the event of becoming unwell.

Figure 7.12

Key theme 12: Lack of information on subsidised breaks – Many service users and cared for persons noted that they felt that there was not enough accessible information on subsidised breaks. It is important to note that this is also a strong theme that emerged in the questionnaire within the service user and cared for person population - twelve people identified this as a potential barrier.

When compared, there are strong similarities between the most popular answers in the questionnaires and focus groups in response to the question 'what might make it difficult for you to have a break?' The three top choices in the questionnaire also emerged as key themes within data generated in the focus groups, suggesting that these are pertinent issues. There are also some similarities and differences in the key themes identified by carers and service users and cared for persons.

Cost was one of the similarities in the key themes identified and is displayed in figures 7.1 and 7.7. Another similarity is 'medical issues / health problems' which is illustrated in figures 7.6 and 7.10. The focus group feedback links in strongly with the feedback in the questionnaire response in table 7. Medical issues was selected by the largest amount of people in the questionnaire. A further similarity in the key themes that emerged is 'adequate support' which is demonstrated in figures 7.2 and 7.9. Once again the focus group feedback ties in closely with the questionnaire feedback in table 7. Adequate Support was the second most selected potential barrier identified by participants that completed the questionnaire. There is a strong correlation between the questionnaires and focus group responses in relation to medical issues and adequate support. However, although cost was a key theme that emerged in the focus groups, it was almost the lowest potential barrier to accessing a break identified in the questionnaire with only two participants selecting this. Another link between the feedback in the questionnaires and focus groups is 'unsure how to access services'. This was the second most popular choice in the questionnaire and also a key theme that emerged from the views of service users and cared for persons during focus groups.

There were also key themes that emerged that were particular to carers and particular to service user and cared for persons. For example, themes that arose from carer feedback were; relationship strain, accommodation and dietary requirements. Noteworthy points were made about dietary requirements and accommodation, in particular, sleeping arrangements (bunk beds), as discussed in figure 7.4. However, relationship strain was quite unique to carers as a key reason for needing a break but also an aspect that can make it very difficult to have a break. Good examples of relationship strain were provided in figure 7.5 where carers discuss internal feelings of guilt or actively being made to feel guilty by the cared for person.

Key themes that were particular to service users and cared for persons are; responsibilities/commitments, safety (feeling safe) / back up plan and lack of information on subsidised breaks. The need for the feeling of safety and having a backup plan was quite unique to people who use services and cared for persons. This did not appear to be an issue for carers.

HOW IS IT GOING TO WORK?

Q.8 – If taking a short break, who would you like to be with you (if anyone)?

Questionnaire

Table 8 illustrates the response to question 8 in the questionnaire. Respondents were asked to tick all that apply.

Table 8

	Service user	I have an unpaid carer and support	Unpaid carer	Total
No one	2	1	1	4
Unpaid Carer	4			4
Support worker	5			5
Group of service users	8			8
Group of carers	1		2	3
Family or friend	13	2	2	17
Other, please specify	Befriender			

Table 8 illustrates quantitative data: The table demonstrates that the most popular choice of who you would like to be with you (if anyone) is 'family or friend'. The next most popular choice was 'group of service users' followed by 'support worker' as the third most popular choice. One questionnaire respondent stated "befriender" as an option in the additional comments box.

The same question was also asked in the focus groups and key themes have been generated based on the respondent's answers.

Focus Groups

UNPAID CARERS

Key theme 1: I want a break without the cared for person

Figure 8.1

<i>"I don't want the person I care for on the break"</i>
<i>"I don't think my daughter would want to go on a break with me and I need a break from my caring role"</i>
<i>"I wouldn't know how to care for my brother on holiday, he is a 24hr voice hearer and he has little motivation to do things"</i>

Key theme 2: I would prefer a break as part of my group or with other carers

Figure 8.2

<i>"Other carers"</i>
<i>"I liked having a break with mixed carers"</i>
<i>"We have been away as a group before, it was great, you come home feeling recharged"</i>

SERVICE USERS AND CARED FOR PERSONS

Key theme 3: I would prefer a break as part of my group

Figure 8.3

<i>"I have day to day problems, so, family like my mum or a group residential, where there can be mutual support and understanding"</i>
<i>"I would like to go with the OCD group for a break"</i>
<i>"With the group (Dundee SUN) but also get the chance to do your own thing too"</i>
<i>"The rest of the group, like a residential"</i>

Key theme 4: I would prefer a worker with me

Figure 8.4

“Someone who understands me, like my support worker”
“Nurse”
“A support worker or member of staff”

Key theme 5: I would prefer my carer / supporter with me

Figure 8.5

“My mum, she is my carer”
“My partner or daughter as they know how to deal with my blackouts”
“My mum”
“Someone I trust”

Figure 8.1 – 8.5 illustrates qualitative data: From the data gathered during the focus groups it became apparent that unpaid carers and service users and cared for persons had one similarity in their response. They identified they would like to go away as part of their group or with their peers. This was with other carers if they were a carer or other service users if they were themselves a service user. This point was illustrated in figure 8.2 and 8.3. However, carers stated in figure 8.1 that they did not want to have a break with the cared for person and needed a break from their caring role. This is in contrast to the opinions of service users and cared for persons who stated they would like a break with their carer/supporter as detailed in figure 8.5. An additional theme that emerged with the service user and cared for population is that they would prefer a worker with them on a break, as identified in figure 8.4.

There were similarities in the response within the questionnaires and the themes generated in the focus groups. The questionnaire highlighted preferring a break with a group of service users and also a support worker as two of the three most popular choices selected, illustrated in table 8. Nevertheless, it is important to note that more service users and cared for persons completed and provided feedback in the questionnaire than carers. This may be indicative of the top choices which emerged, in particular going on a break with a ‘support worker’ and ‘other service users’. Carers are not likely to have opted for these choices due to the fact they do not identify themselves as service users and are less likely to have a support worker.

Q.12 – What are the most important things to consider when booking your break?

The key themes below have been constructed from qualitative data which has been gathered from the questionnaires in response to question 12.

UNPAID CARERS

Key theme 1: Easy process

Figure 9

<i>“Easy process”</i>
<i>“Not difficult to arrange”</i>
<i>“How to arrange it”</i>
<i>“Easy process, not difficult to arrange”</i>

SERVICE USERS AND CARED FOR PERSONS

Key theme 2: Cost

Figure 9.1

<i>“Affordability and easy to arrange”</i>
<i>“It’s stress free, pre-planned and not too expensive”</i>
<i>“Cost is important. If it’s too dear, people may not be able to afford a break, but might really need one”</i>

Key theme 3: Easy process

Figure 9.2

<i>“Not difficult to arrange”</i>
<i>“It must be easy to arrange and a stress free process. There needs to be someone to do it for you or help you”</i>
<i>“Cultural interests and not difficult to arrange”</i>

Key theme 4: Accommodation

Figure 9.3

<i>“That it is a nice hotel with good food and breakfasts”</i>
<i>“Relaxing environment and not too far away”</i>
<i>“Good vegetarian menu, interesting activities too me personally, so I’m not bored”</i>
<i>“Ground floor”</i>

Key theme 5: Support is available

Figure 9.4

<i>“Make sure I have my tablets on me. Penumbra helped me meet a doctor and get my prescription on a previous break, as I forgot my tablets”</i>
<i>“Knowing other people are around who understand me. I am half deaf as well, so sometimes people think I’m ignoring them”</i>
<i>“Who is going to accompany me? I can afford to travel as long as it’s not extortionate, but having the right person to travel with me, who understands my needs, in case I felt unwell”</i>

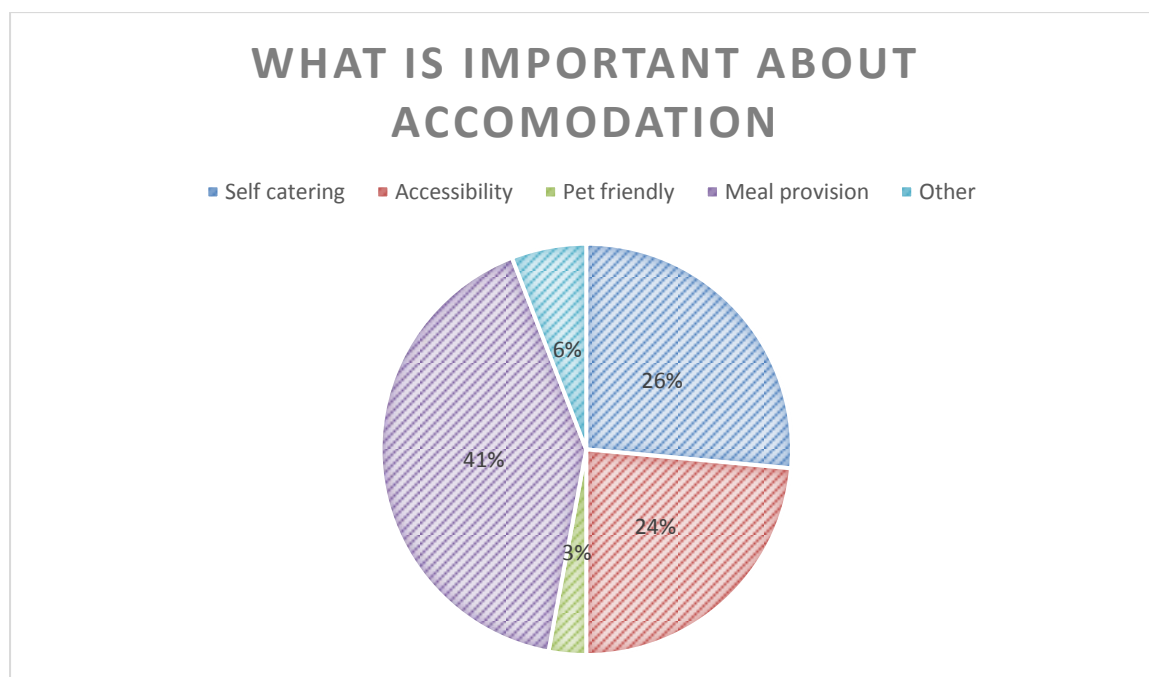
Figure 9 – 9.4 illustrates qualitative data: When exploring the most vital issue when booking your break, only one key theme emerged, it needs to be easy to arrange. This key theme was also similar for service users and cared for persons who also identified that booking a break needs to be an easy process. However, service users and cared for persons also highlighted more things that were important to them for consideration. For example; cost, accommodation and that support is readily available.

Q. 17 – If your break involved staying somewhere, what would be important about the accommodation?

Questionnaire

Table pie chart below in table 10 includes responses from all participants in the questionnaire amalgamated into one table. This provides an overview of what is important about accommodation.

Table 10



When considering accommodation, 'meal provision' was most important to people with 41% of respondents selecting this. 'Self catering' was the next most popular choice selected by respondents with 26% of respondents selecting this option. This could perhaps be viewed as re-enforcing the most popular choice of meal provision. It became evident in question 18 of the questionnaire that for some people, the food available (or not available) could be a potential barrier to accessing a break. More so for people who were vegetarian, had food intolerances such as Gluten and had health problems such as coeliac disease. Accessibility was also important to respondents when considering accommodation, with 24% of participants selecting this.

CONCLUSIONS AND RECOMMENDATIONS

If people are involved as equal partners in designing the short break services, we should see better outcomes for said individuals and also a wider population of people who may use the service, resulting from good quality breaks. It has become apparent from undertaking the 'It's all about the break' consultation that there is a real need for high quality 'individualized' and 'personalised' types of short breaks which are tailored to meet individual need and preferences. Breaks also need to be available to people at the right time, which is important. This is in contrast to the out-dated 'one size fits all' approach to service delivery and more in line with the shift towards Self Directed Support (SDS). Though the majority of participants (67%) had not previously accessed a subsidised short break in the past, it has become apparent that there is an appetite to access subsidised short breaks for respite. A significant majority of the 67% of people who had not had a break said that they were not aware of this type of support. Nevertheless, individuals were able to clearly identify the benefits and personal outcomes of having relevant, useful and flexible breaks, but perhaps more importantly there was an appetite for having a level of autonomy to utilise an individual or group budget - but to also co-produce the break and or activities. An extensive list of desirable destinations, activities, new skills and hobbies has been compiled by carers and service users and cared for persons which can be requested to inform the pilot.

WHAT DO YOU WANT FROM A BREAK?

Improved health and wellbeing outcomes for individuals was seen as the biggest benefit by both carers and service users and cared for persons. For carers, a break helps individuals to maintain their own health and wellbeing and consequently their unpaid caring role. This is clearly explained by a carer who said "helping us to have a break can enhance our health and wellbeing". Without access to short break respite, we may see an increase in carers with poorer health. Although one carer said "we really need this, not having a break can run you into the ground" this notion was echoed by many carers. Without a new model of short breaks we may see an increase in the breakdown of relationships where there is a caring role and also the loss of capacity of unpaid carers to continue with their caring role. Being able to have some enjoyable and relaxing time away from the cared for person is critical for carers. This is evident and is illustrated by a carer who simply states having a break "helps you to carry on caring".

A significant number of carers said that having a break away from the cared for person is beneficial. A number of examples were provided to explain this. One carer stated that a break away from the cared for person "*Helps you to re-charge the batteries and go back in a better frame of mind to my caring role*". Within a focus group another carer said that she would not know how to care for her brother away from the home environment, who she described as a '24 hour voice hearer' who appears to lack the motivation to do things. This notion highlights the fact that not all

carers would feel confident in having a break away with the cared for person, depending on their needs and would in fact need to be supported in some way to do this. Of all the carers engaged during the consultation, only one said they would benefit from a break with the cared for person. In this instance, the cared for person is a young person and the carer viewed having a break together as 'mother and son time', 'doing something different together'. People who identify having a break together (carer and cared for) as beneficial should not be excluded from accessing a break from the pilot. There are some carers who may need a break and change of scenery who would simply not go away without the cared for person. Being refused a break could be detrimental to a carers health and wellbeing.

Carers went on to say that going on a break is probably not something that most people would choose to do on your own. A significant number of people felt that going away as part of a group was probably more beneficial for many carers. It was also described as a sense of 'camaraderie' by being in the company of others you can identify with - as they are 'in the same boat'. It was stated in a focus group that "you get a lot of support from other carers" which includes "sharing information about services" which is useful. Word of mouth still appears to be how a lot people hear about what is available in Dundee. Another individual who had been on a break as part of a group (Cairn Fowk) in the past said, that's when she felt she really gelled with her peers and made genuine supportive friendships. These are the types of valuable connections people make which help people to feel less isolated. It appears that by supporting carers groups to go on breaks together you increase the supportive networks around the individuals which is positive and for some it is a real life line.

National Research (from Carers UK) indicates that over 50% of carers say that they are not receiving enough support and that most of the public think that emotional strain would be a top potential issue if they were an unpaid carer. Taking this into account and also what we have learned locally during the consultation it is unmistakable that there is a clear and unique role for short break provision in supporting caring relationships. The breaks provided will give carers more opportunities to enjoy a life outside of their caring role by providing them with a subsidised break or simply giving them time to themselves. As a result, carers of people with mental health issues will hopefully feel better supported, more able to cope and more able to sustain their caring role. In particular, carers who are less likely to access current support and carers whose needs are not being met by current models of service provision.

For service users and cared for persons, improved health and wellbeing is also one of the greatest benefits identified from having a break. However, a break was also viewed as an important part or next step in an individual's recovery. People identified that they would benefit from having a change of scenery, a break from their everyday routines and making positive memories in a nice relaxing environment - this is not surprising. What is interesting to learn, is that with some mental health

needs in particular, a break away can actually reduce certain symptoms. In the examples collected during the consultation, people who have Obsessive Compulsive Disorder (OCD) shared their experience which illustrates this point. An individual with OCD said *“When I go away my OCD symptoms reduce, not intensify”* another individual with OCD said that from time to time it is really beneficial to *“get away from the home environment. OCD is worse when you are in your own environment”*.

In dialogue with other service users and cared for persons during focus groups, going on a break was viewed in a similar vein to ‘graded exposure’. This was explained to the researcher as getting the support you need to re-build your confidence slowly by trying new things and exposing yourself to old or new situations in which you have lost your confidence, feel anxious or feel completely out of your comfort zone. By exposing yourself to these situations you are taking the next step in trying to move beyond the invisible constraints you have may have placed on yourself. A direct quote which is fitting with this notion is *“Try new things and get involved with new people. It is the next step in recovery for lots of people”*. On this basis it is clearly identifiable that short break respite provision has a unique contribution to make in terms of health and wellbeing outcomes but also recovery focused outcomes for individuals who are cared for or use services. In particular, those with long term and enduring mental health needs.

Carers and service users and cared for persons identified having a break as part of a group as a desirable option. This was a strong theme which emerged in each of the focus group discussions and also a substantial amount of questionnaire feedback. Comments that demonstrates this point are; *“It’s something you wouldn’t do on your own”* and it would be great to have *“a group residential where there can be mutual support and understanding”*. It was also recognised that for some individuals who were part of the consultation, they felt like they were not in touch with other people who wanted a break. In particular, those who used services and did not have unpaid carers. For these individuals, a group break has the potential to be a really positive, health promoter. Only four people in total out of the sixty people who took part in the consultation said that they would like to have a break on their own. This is an important aspect for consideration during the pilot period. This suggests that there should be more than one option available - individual breaks, the opportunity to have a break as part of a group or to be matched with other suitable individuals. It would be useful to have these options available to individuals during the pilot phase and thereafter.

It is also important to acknowledge that as well as unpaid carers stating they need a break from caring, people who use services and cared for persons also identified that unpaid carers do actually need a break from their caring role and showed awareness of the potential benefits this can have. Whether this was the carer having a break with or without the cared for person or the cared for person going on a break and the carer benefitting as a by-product by spending some time apart. This would enable a carer time to enjoy doing things for themselves like maintaining friendships,

support networks, pursuing their own hobbies and interests and ultimately a having a life outside of their caring role. This consultation has undoubtedly highlighted the need to support the extremely important role of unpaid carers.

WHAT DO YOU WANT A BREAK TO LOOK LIKE?

Each individual who engaged in the consultation had a good idea about the individual outcomes they want from short breaks. It was a very close call between the two choices of 'design your own break' or 'choose from a menu' with an almost equal number of people selecting each option. Nevertheless, the option to design your own break was the most popular choice. This shows a real appetite to be in control and co-produce bespoke arrangements for their break. This demonstrates that we need to support and inspire individuals in creative ways to identify the type of 'individualized' break they are looking for. Facilitating the exploration of potential choices available to them in terms of destination, duration, desirable activities, structure and the level of support required to name but a few.

It is apparent that the participants could benefit from something different, whether designing their own break or not. For the people that opted for choosing from a menu, it is evident they still want something different, but perhaps did not want to experiment, orchestrate or design their own package. Possibly the thought of designing their own break felt like an onerous task and even more daunting if this was to be their first ever break, or the first for a very long time. It appears that people in this group could benefit from having a greater and updated menu of provision to inspire them and to take some of the demanding work out of setting up bespoke short break arrangements.

An additional point to note is that all of the participants engaged in the consultation who have been on a short break in the past said they would like to design their own break. Perhaps this can be interpreted as increased confidence for said individuals and furthermore improved self-management. Having already had a break under more traditional short break or residential models, perhaps this is next step, moving towards having more choice and control over their respite arrangements and to fulfil their own goals and aspirations. This notion can be supported by comments made during a focus group discussion. A service user said that *"getting help to have a break and starting off small can do wonders for a person. It can give a person the confidence to go on and build on the experience by going on to arrange their own break in the future after experiencing the benefit of getting away..."*

When exploring people's expectation of the duration of a short break, the shortest time the majority of people considered a break to be was a long weekend, which is generally viewed as three to four days by respondents. The options of two to three days were also quite popular, however a few people added their own comments to the questionnaire suggesting a week in duration. An additional point to note is that during discussions in regards to the question of duration, several individuals said that

they would not want travelling time to outweigh the actual time spent on the break. This is noteworthy for the pilot phase, more so, for people who do not want to design their own break and would opt to choose from a pre-set menu of breaks.

When investigating people's expectation of the frequency that people would like to see short breaks available to individuals, the most popular choices were quarterly and yearly. There was only 1 % difference between the two with quarterly being most popular. Yearly is perhaps a more realistic frequency in terms of the funding available now and in the future. Nevertheless, there is no question that for some people a break every three to four months would have great health and wellbeing benefits. Particularly when considering some of the points raised previously within this paper around the mental health symptoms decreasing when away from their own environment. As well as for carers who are supporting individuals with complex, severe and enduring mental illness.

A critique of the design of the question of frequency is that there was not an option to select 'six monthly' as a choice. On reflection, this may have had the potential to be a popular choice. If the consultation were to be repeated, having the option to select 'six monthly' would be included in the options to choose from.

WHAT DO YOU FEEL MIGHT GET IN THE WAY?

When exploring participant's views around what they felt might get in the way or make it difficult to have a break, a strong association developed between the most popular answers in the questionnaires and focus groups when the two sets of data were compared. The three top choices in the questionnaire also emerged as key themes within data generated in the focus groups. This suggests that these are pertinent points to be considered during the pilot phase.

The top three barriers to accessing a break in the data gathered in the questionnaires are in order of importance as follows; medical issues, unsure how to access services and adequate support. Medical issues emerged as a key theme in the focus groups among carers and service users and cared for persons, as did adequate support. The option, 'unsure how to access services' emerged as a key theme in the focus group data within the service user and cared for person's population. This is almost in complete contrast to the unpaid carer population who engaged in the consultation, in which only one unpaid carer overall identified lack of information as a potential barrier.

To further explore this theme, referring back to the opening question of the focus groups and questionnaire – have you ever had a break? The overall response showed that more carers had accessed a break than people who used services. 20% of carers said they have had a break compared to 13% of service users and cared for persons who said they have had a break. This may re-enforce the point made by service users and cared for persons viewing 'unsure how to access services' as barrier to having a break. Perhaps a bigger uptake of breaks by carers is

indicative that the unpaid carer population have more awareness of short breaks and respite provision than the service user and cared for person's population. Even more so for individuals who do not have a carer. Although carers are a priority of focus and must benefit from a break in this particular short breaks pilot, it may be fair to say that more work needs to be done to promote and raise awareness of short breaks provision for the service users and cared for person's population for the future, beyond the pilot phase.

There are some similarities identified by carers and service users and cared for persons in relation to perceived barriers to having a break. Medical issues and health problems which are closely related, were similar in the key themes that emerged. There is a need for these to be taken into account. This can include what support (if any) or planning would need to be considered or put in place in order for individuals to have a break. For example, pre planning and ensuring all of an individual's medication is organised and collected in advance of a break.

Cost is also a key theme that is important to all participants. This highlights the need for affordable subsidised breaks - failing this, people may not manage to afford having a much needed break from caring or their caring role or routine. Adequate support was another similarity identified by both carers and service users and cared for persons. Carers said they needed to know that the right kind of 'trusted support' was in place for the cared for person before they would feel comfortable in booking and going away on a break, in particular if the break involved staying somewhere.

Whereas, service users and cared for persons said they needed to know that adequate support would be in place before they would feel confident enough to try something new and have a break. This group highlighted the fact that how they may feel day to day is unpredictable so they are unable to foresee if they will have "a down spell" while they are on a break. This need for assurance that support is on hand and that everything will be managed well in the event of becoming unwell is understandable. This will include a varying level of support required for each different individual accessing a break. Some people may need up to 24 hour support from experienced staff or support workers and some people may require lower level supports, from peer volunteers for example. These levels of support must also be considered with equal importance for cared for persons who are remaining at home while their carer is on a break.

There are also some differences in the key themes that emerged highlighting a different set of prerequisites which are equally important to both groups. Carers highlighted relationship strain as a key theme which was unique to this group. In some cases relationship strain is one of the main reasons for a break, potentially however, it can also be the very thing that made it difficult for a carer to have a break. This may be because of internal feelings of guilt or the cared for person knowingly or unknowingly making their carer feel guilty for leaving them to go on a break. One carer shared her experience about relationship strain. Her daughter

became distressed, which presented in a change in behaviour just before she was due to go on a short break for respite. This type of situation can be difficult for both the carer and cared for and either party may require some support in managing their feelings about having a break apart. Each individual cared for person should be very much at the centre of the planning and decision making process, enabling people to feel empowered and that they have a level of autonomy and choice in regard the supports they receive in their carer's absence. Perhaps by being at the very centre of planning and decision making may help to reduce individual's anxieties, concerns or any negative feelings about having a break apart.

Individuals who use services and cared for persons highlighted responsibilities and commitments, which included having children and pets that would need to be accommodated on a break or looked after. Some individuals may wish to take their pets with them on a break and if designing their own break, they could choose somewhere that is pet friendly. However, for those who do not wish to design their own break, there should be pet friendly options available as part of an updated pre-set menu. This group also highlighted safety or the need to 'feel safe' and the need for a backup plan. In case something were to go wrong or someone started to feel unwell. For example, if an individual forgot to bring their medication with them, they may need some reassurance and support to manage the situation and source the medication they need. Service users and cared for persons said they would feel more confident if they knew that 'trusted people' would be available to provide this type of support if required.

An important aspect to highlight in regards the data sample is that there was a lack of up take in the consultation from the Black and Minority Ethnic (BME) communities. There were only two individuals engaged where English is not their first language. These individuals took part in a focus group. One of the individuals said that they felt that language can be a barrier. They said that they found it hard to understand new people and they felt that new people may struggle to understand them. This appeared to impact this individual's confidence when thinking about having a break. Perhaps this would have emerged as a key theme rather than a point to note, if more people were engaged where English is not a first language. In addition, no one selected cultural needs in response to question eighteen which was exploring barriers. Possibly if more individuals from BME communities had been engaged in the consultation, we would have seen cultural and religious needs emerge as a key theme for consideration as opposed to not selected at all. People should be supported to express their religious and cultural beliefs if applying for and planning a break from the short breaks pilot and this is something to be mindful of during the pilot phase and beyond.

A critique of question number eighteen in the questionnaire (Please see Appendix 1) is that participants were asked to pick or state three potential barriers that were relevant to them and then to rank the choices in order of importance. On reflection, it now seems that latter part of the questions was unnecessary. Not everyone who

completed the questionnaire ranked their choices in the questionnaire and this has not affected the validity of the data collected. If the consultation were to be repeated, participants would not be asked to rank their selected barriers in order of importance. The number of people selecting each barrier would suffice as a guide to which were most pertinent.

HOW IS IT GOING TO WORK?

As stated previously in this paper we know that most people do not want to go on a break alone. Only a small number of people out of the sixty people overall who took part in the consultation said they would like a break alone. Two carers said they would like to go with family or friends and two said they would like to go on a break alone. The majority of carers said they would prefer a break without the cared for person, with other carers or as part of pre-existing carers groups they attend. Service users and cared for persons said they would like accompanied on a break by; family or a friend, a group of service users, a support worker or their carer.

As noted earlier in the paper, only one carer who participated in the consultation said they would like a break with the cared for person as the person they cared for was their child. This is in contrast to the cared for persons and service users opinions, as one of this groups more popular choices was to go on a break with my carer. Only two service users and cared for persons engaged said they would like a break alone.

It is clear that carers are aware that they need a break away from the cared for person to maintain their health and sustain their caring role. As noted earlier in this paper, cared for persons and people who use services did acknowledge that a carer having a break away from the cared for person would be beneficial for the carer. Nevertheless, going away with my carer still proved a popular choice with this group. Both carers and service users and cared for persons identified going away with peers as part of a group as a popular choice with the benefits of mutual support and understanding and making friendships. However, the service user and cared for population also highlighted going away with a support worker which ties in with the need for feeling safe and supported while on a break, which was highlighted more than once by this group during the consultation.

When exploring the important things to consider when booking a break carers only identified one key theme as important to them. This was that booking a break should be an easy process. This was reinforced by people who use services and cared for persons whom also said that booking a break should be an easy process. However, they also said that the accommodation, cost and support being available were important to them. These are not new themes within the research, and have come up in relation to other questions many times. If anything, these key themes reinforce the importance of a break being affordable. The accommodation must be suitable for each individual's needs. Knowing that the right kind of support will be on

hand from people who have an understanding of your specific needs in case of a crisis or feeling unwell, gives peace of mind.

When considering what is important about accommodation, the three most important things to people in order of importance are; meal provision, accessibility and the option to go self-catering. Perhaps by going self-catering, people may feel like they have more control over this element of their break and will avoid any disappointment with the menus on offer. Some participants said that from experience, there is not always the best choice of vegetarian meals on offer. Going self-catering would also mean people are well prepared, which would allow individuals to maintain their specific diet, which is important if individuals have particular dietary requirements which has been discussed previously in this report. A point for further consideration to be taken into account when considering meal provision on offer in establishments during the pilot phase is that the BME community were under represented as part of the data sample. Perhaps we would have seen the need for Halal and or Kosher food to be available.

Accessibility is important and was also a feature of discussions in the focus groups and questionnaires in response to other questions. When exploring accessibility, this should include sleeping arrangements, such as the appropriateness or not of bunk beds, as well as the accessibility of the room in terms of location, stairs and the toilet facilities. Some individuals may need to be on the ground floor and require an en suite bathroom with a walk in shower, with shower aids for example. For individuals who have a disability or mobility issues, it would be advantageous for any potential accommodation to be checked out in advance on the www.disabledgo.com website. It provides free accessibility information about establishments which enables people to have more choice, control and independence.

There were a number of relevant and pertinent key themes that emerged during the consultation which are valuable and will help to inform the “It’s all about the break!” pilot. However, there were some themes that surfaced more than once in response to different questions asked in the questionnaire and focus groups. The key themes that emerged more than once are; cost, improved health and wellbeing, preferring a break with other carers or service users, preferring a break without the cared for person, accommodation and adequate support.

A final critique of the consultation is that no young carers were engaged in the consultation. This takes us back to our rationale for probability sampling. The sample was targeted because of the probability that the sample would provide a good cross section of people with relevant lived experience which the consultation was seeking to explore. The PSP were looking for involvement from individuals who were 16 years and over, but unfortunately no one in their teens or early twenties expressed interest in taking part. Everyone who participated in the consultation were over the age of 30. It is arguable that the research has not encapsulated the younger carer’s voice, which may have brought a different and valuable perspective to the research.

The very nature of the time of day when focus groups were held, happened to be during education hours. This would have had an exclusionary effect on young adult carers and people who were unable to attend due to employment. If the research were to be repeated and young adult carers were to show interest in being included, focus group would need to be held at a variety of times, in particular out with education hours to accommodate this. Dependent on the decisions made about the types of short break provision, there may be potential to benefit young carers, if they person they care for (a parent with mental health needs) receives a break, the young carer will have more chances to participate in recreational activities.

A health warning for the pilot phase is that if people apply for breaks, but perhaps do not clearly meet the criteria to access a break from this particular funding, that these individuals are encouraged and supported to apply to access a short break elsewhere. These individuals could be directed to apply for a break with Dundee Carers Centre, Scotland Association for Mental Health and Penumbra, to name but a few. Individuals who do not clearly meet the criteria should be treated with equal importance to those who do meet the criteria. This approach should be more than a mere signposting exercise, as some people do not follow through on chasing up opportunities unless they are supported in some way to do so. If we get this right, we should see less people falling through any gaps in provision during this test of change.

Appendix 1

PSP Short Breaks Questionnaire

“It’s all about the break!”

Funding has been secured to look at new ways to provide short breaks/respice which will best meet individual’s and carer’s needs. Local people, who use Mental Health Services, and their unpaid carers, have shared their views about the needs for short breaks supports. Because of what people have said, a number of organisations in Dundee have come together to design new short breaks to meet the needs of adults who need substantial care and support and to support their carers.

The PSP (Public Social Partnership) aims to develop supports that are right for people, cost effective and genuinely enable people to achieve their own personal outcomes. As well as people experiencing useful and flexible short breaks.

Thank you in advance for taking the time to complete this questionnaire. This questionnaire is for adults with mental ill-health, as well as unpaid carers. Unfortunately, taking part in the PSP Short Breaks consultation does not mean you are automatically eligible to receive a short break. However, by taking part, you are having your say in shaping service delivery in Dundee.



For the purpose of this questionnaire, the term ‘short break’ means a break from the usual day to day routines for a person who has care and support needs / and or the person who supports them (known as their unpaid carer). Short breaks are often referred to as ‘respite’. The term ‘service user’ means individuals who use Mental Health Services. The term ‘cared for person’ means an individual who receives informal care and support from a family member or friend (unpaid carer). The term ‘unpaid carer’ means an individual who provides help, support and assistance to someone with mental ill-health, and is not paid for doing so.

(Please tick which apply to you)

I am a service user	
I am a cared for person	
I am an unpaid carer	
I am/have an unpaid carer and also have support provided	
Other, please specify	

(Please circle)

Age: 16 - 24 25 - 40 40 - 55 55 - 65 65+

(Please circle)

Gender: Female Male Other

(Please circle)

If you are a carer, how old is the person you care for?

Age: 16 - 24 25 - 40 40 - 55 55 - 65 65

(Please circle)

1) Have you ever had a short break? Yes No

2) When did you last have a short break?.....

3) Who provided it?.....

4) What was your break like?

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5) What was good about your break?

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6) If you were taking the break again, what would you change?

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7) How should a break benefit you?

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.....

8) If taking a short break, who would you like to be with you (If anyone)?

(Tick all that apply)

No one	
Unpaid carer	
Support worker	
Group of service users	
Group of carers	
Family or friend	
Other, please specify	

9) What is the shortest time you consider a break to be?

(Please tick 1)

Less than half a day	
Half a day	
Up to 2 days	
Up to 3 days	
Up to 5 days	
A long weekend	
Other, please specify	

10) What type of frequency would you like to see available?

(Please tick 1 or 2 boxes)

Weekly (little amount of time and often)	
Fortnightly	
Monthly	
Quarterly (every 3 months)	
Yearly	

11) Would you like to choose from a menu or design your own break?

(Please tick one)

Choose from a menu	
Design my own break	

12) What are the most important things to consider when booking your break?
(e.g. easy process, not difficult to arrange, cultural considerations etc)

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13) What restrictions (if any) are there on how far you can travel?

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14) What style of break would you like?

(Please tick which apply to you)

Creative	
Relaxing	
Adventure	
Holistic / Therapeutic	
Learning / New skills	
Other, please specify	

15) What is most important to you when taking a short break?

(e.g. by the sea, special dietary requirements, near a church or mosque etc)

(Please tick the most important to you)

Location (e.g. by the sea)	
Activity (e.g. walking or cycling)	
Cultural needs (e.g. special dietary requirements)	
Cost	
Other, please specify	

16) What do you want to get out of a short break?

(Please tick the most important to you)

Escape	
Change of routine	
Making positive memories	
Fun	
Improved wellbeing	
Other, please specify	

17) If your break involved staying somewhere, what would be important about the accommodation?

(Please tick the most important to you)

Self catering	
Accessibility	
Pet friendly	
Meal provision	
Other, please specify	

18) What would make it difficult for you to take a break?

Please tick 3 which apply to you. **Can you also please rank your choices in order of importance from 1 being most and 3 being least important.**

Potential Barriers to taking a break.	Tick 3 which are important to you.	Rank of importance from 1 – 3 with 1 being most important
Medical issues		
Meal provision		
Responsibilities / commitments		
Appropriate accommodation		
Adequate support		
Transport		
Accessible toilets		
Unsure how to access services		
Cultural needs		
Mobility		
Other, please specify		

There will be a follow up event on the 13th of May to share what we have learned from the process, questionnaires and focus groups. This will also be an opportunity to co-design the types of options available in Dundee for the pilot period.

Do you want to be part of a group to take the ideas forward?

Yes No

Contact details:

Name	Address	Telephone number and email address

Appendix 2

Focus Group

PSP Short Breaks Consultation

It's all about the break

Discuss: Knowledge & Current Short Break / Respite provision available in Dundee. (5 -10 mins)

Ice Breaker: M&M's game (picked from a choice of 3 by carer at PSP Sub-group meeting) (5 mins)

Each participant given a bag of M&M's they pick one out of their bag and depending on the colour they choose, they answer a question.

Red – Something about yesterday?

Orange – Something you do well?

Yellow – Your favourite colour?

Blue – Something you learned recently?

Brown – Something you can't live without?

Green – Something you watch / listen to?

(There will be 2 facilitators with 1 taking notes at table from discussion)

Topic 1 – Current knowledge & Experience

(Facilitator to record answers)

Have you ever had a short break?

When did you last have a short break?

What was your break like?

Who provided it?

What was good about your break?

Was anything bad about your break?

How should you benefit from a short break?

If taking a short break, who would you like to be with you (if anyone)?

Topic 2 – What type of break would you like to see available

Ask participants to bear in mind current provision discussed at the start of focus group.

Facilitator to use following lists to inform the discussion and stimulate ideas (Facilitator at table to help write on flip chart if people are struggling)

Suggested breaks:

Meet friends, learn a new skill / hobby (making jewellery, learning how to use computers), join a community group, boat excursion, coach trip, shopping trip, travel with support, theatre break, museum/gallery break, UK holiday, weekend away, residential break with others for mutual support

Suggested activities:

Craft, art, outdoor activities

New skills / Hobbies:

Making jewellery, sewing, learning how to use computers, photography

Brain storm / Mind map on the following topics on flip chart (1 flip chart sheet per topic)

- **Breaks Away**
- **Activities**
- **New hobbies / skills**

There will be 2 frequency Tables which participants can put 1 or 2 sticky stars next to preferred choice

1. What is the shortest time you consider a break?

(1/2 day, 1 day, 2 days, 3 days, 4 days, long weekend)

2. What type of frequency would you like to see available?

(weekly, monthly, fortnightly, quarterly, yearly)

There will be a table which participants can put 1 or 2 sticky stars next to the **style of break people would like to see available?** (relaxing, adventure, holistic, therapeutic, learning, other)

There will also be a table which participants can put 1 sticky star next to the **preferred method of selecting a break** (choose from a menu or design your own break).

Topic 3 – Short Breaks Preparation / Barriers / Special Considerations

What is important to you when taking a short break?

Location, activity, cost, distance other (Facilitator to form a list) **What would make it difficult for you to have a break?**

Facilitator to inform discussion and stimulate ideas (location, transport, suitable facilities, cost, access, meal provision, medical issues, unpredictability of condition, suitable accommodation, support, responsibilities)

(Each participant to write 3 barriers on post-it notes. Next they rank the importance of each barrier with 1 being most important and 3 the least, by numbering the post-its)

There will be a table asking: **What do you want to get out of a short break?** (escape, change of routine, making positive memories, fun, new experience, learning something new)

Each participant to put 1 or 2 stars next to preference

There will be a table asking: **What would be important about accommodation?** (Self-catering, accessibility, pet friendly, meal provision, cost)

Finish

Thank everyone for their time and taking part.

Ask if anyone would like to be part of an on-going reference group and take details.