The purpose of this questionnaire is to help understand your fatigue experience and what you are doing while you are using the Fitbit.

Please fill out this questionnaire from \_\_\_\_\_\_\_\_\_ to \_\_\_\_\_\_\_\_\_\_\_. Do this for each hour of the day and night.

In the spaces provided, write the activity **that you feel best describes** what you were doing during that hour of the dayand rate your fatigue on a scale from 0-10 (**0 being no fatigue and 10 being the worst fatigue**).

Example

|  |  |  |
| --- | --- | --- |
| Day 1 | Afternoon | Fatigue |
| Hour Beginning At | Activity |  |
| 12:00 noon | Prepare Lunch, Eat Lunch | 4 |
| 1:00 p.m. | Clean Kitchen | 7 |

**Fatigue/Activity Record**

Initials\_\_\_\_\_\_\_ Age\_\_\_\_\_\_ Day/Date\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

|  |  |  |
| --- | --- | --- |
| **Day 1** | **Morning** | **Fatigue** |
| Hour Beginning At | Activity |  |
| 4:00 AM |  |  |
| 5:00 AM |  |  |
| 6:00 AM |  |  |
| 7:00 AM |  |  |
| 8:00 AM |  |  |
| 9:00 AM |  |  |
| 10:00 AM |  |  |
| 11:00 AM |  |  |
| 12:00 PM |  |  |
|  | **Afternoon** |  |
| 1:00 PM |  |  |
| 2:00 PM |  |  |
| 3:00 PM |  |  |
| 4:00 PM |  |  |
| 5:00 PM |  |  |
| 6:00 PM |  |  |
| 7:00 PM |  |  |
| 8:00 PM |  |  |
| 9:00 PM |  |  |
| 10:00 PM |  |  |
| 11:00 PM |  |  |
| 12:00 AM |  |  |
|  | **Morning** |  |
| 1:00 AM |  |  |
| 2:00 AM |  |  |
| 3:00 AM |  |  |

**Fatigue/Activity Record**

Initials\_\_\_\_\_\_\_ Age\_\_\_\_\_\_ Day/Date\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

|  |  |  |
| --- | --- | --- |
| **Day 2** | **Morning** | **Fatigue** |
| Hour Beginning At | Activity |  |
| 4:00 AM |  |  |
| 5:00 AM |  |  |
| 6:00 AM |  |  |
| 7:00 AM |  |  |
| 8:00 AM |  |  |
| 9:00 AM |  |  |
| 10:00 AM |  |  |
| 11:00 AM |  |  |
| 12:00 PM |  |  |
|  | **Afternoon** |  |
| 1:00 PM |  |  |
| 2:00 PM |  |  |
| 3:00 PM |  |  |
| 4:00 PM |  |  |
| 5:00 PM |  |  |
| 6:00 PM |  |  |
| 7:00 PM |  |  |
| 8:00 PM |  |  |
| 9:00 PM |  |  |
| 10:00 PM |  |  |
| 11:00 PM |  |  |
| 12:00 AM |  |  |
|  | **Morning** |  |
| 1:00 AM |  |  |
| 2:00 AM |  |  |
| 3:00 AM |  |  |

**Fatigue/Activity Record**

Initials\_\_\_\_\_\_\_ Age\_\_\_\_\_\_ Day/Date\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

|  |  |  |
| --- | --- | --- |
| **Day 3** | **Morning** | **Fatigue** |
| Hour Beginning At | Activity |  |
| 4:00 AM |  |  |
| 5:00 AM |  |  |
| 6:00 AM |  |  |
| 7:00 AM |  |  |
| 8:00 AM |  |  |
| 9:00 AM |  |  |
| 10:00 AM |  |  |
| 11:00 AM |  |  |
| 12:00 PM |  |  |
|  | **Afternoon** |  |
| 1:00 PM |  |  |
| 2:00 PM |  |  |
| 3:00 PM |  |  |
| 4:00 PM |  |  |
| 5:00 PM |  |  |
| 6:00 PM |  |  |
| 7:00 PM |  |  |
| 8:00 PM |  |  |
| 9:00 PM |  |  |
| 10:00 PM |  |  |
| 11:00 PM |  |  |
| 12:00 AM |  |  |
|  | **Morning** |  |
| 1:00 AM |  |  |
| 2:00 AM |  |  |
| 3:00 AM |  |  |

**Fatigue/Activity Record**

Initials\_\_\_\_\_\_\_ Age\_\_\_\_\_\_ Day/Date\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

|  |  |  |
| --- | --- | --- |
| **Day 4** | **Morning** | **Fatigue** |
| Hour Beginning At | Activity |  |
| 4:00 AM |  |  |
| 5:00 AM |  |  |
| 6:00 AM |  |  |
| 7:00 AM |  |  |
| 8:00 AM |  |  |
| 9:00 AM |  |  |
| 10:00 AM |  |  |
| 11:00 AM |  |  |
| 12:00 PM |  |  |
|  | **Afternoon** |  |
| 1:00 PM |  |  |
| 2:00 PM |  |  |
| 3:00 PM |  |  |
| 4:00 PM |  |  |
| 5:00 PM |  |  |
| 6:00 PM |  |  |
| 7:00 PM |  |  |
| 8:00 PM |  |  |
| 9:00 PM |  |  |
| 10:00 PM |  |  |
| 11:00 PM |  |  |
| 12:00 AM |  |  |
|  | **Morning** |  |
| 1:00 AM |  |  |
| 2:00 AM |  |  |
| 3:00 AM |  |  |

**Fatigue/Activity Record**

Initials\_\_\_\_\_\_\_ Age\_\_\_\_\_\_ Day/Date\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

|  |  |  |
| --- | --- | --- |
| **Day 5** | **Morning** | **Fatigue** |
| Hour Beginning At | Activity |  |
| 4:00 AM |  |  |
| 5:00 AM |  |  |
| 6:00 AM |  |  |
| 7:00 AM |  |  |
| 8:00 AM |  |  |
| 9:00 AM |  |  |
| 10:00 AM |  |  |
| 11:00 AM |  |  |
| 12:00 PM |  |  |
|  | **Afternoon** |  |
| 1:00 PM |  |  |
| 2:00 PM |  |  |
| 3:00 PM |  |  |
| 4:00 PM |  |  |
| 5:00 PM |  |  |
| 6:00 PM |  |  |
| 7:00 PM |  |  |
| 8:00 PM |  |  |
| 9:00 PM |  |  |
| 10:00 PM |  |  |
| 11:00 PM |  |  |
| 12:00 AM |  |  |
|  | **Morning** |  |
| 1:00 AM |  |  |
| 2:00 AM |  |  |
| 3:00 AM |  |  |

**Fatigue/Activity Record**

Initials\_\_\_\_\_\_\_ Age\_\_\_\_\_\_ Day/Date\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

|  |  |  |
| --- | --- | --- |
| **Day 6** | **Morning** | **Fatigue** |
| Hour Beginning At | Activity |  |
| 4:00 AM |  |  |
| 5:00 AM |  |  |
| 6:00 AM |  |  |
| 7:00 AM |  |  |
| 8:00 AM |  |  |
| 9:00 AM |  |  |
| 10:00 AM |  |  |
| 11:00 AM |  |  |
| 12:00 PM |  |  |
|  | **Afternoon** |  |
| 1:00 PM |  |  |
| 2:00 PM |  |  |
| 3:00 PM |  |  |
| 4:00 PM |  |  |
| 5:00 PM |  |  |
| 6:00 PM |  |  |
| 7:00 PM |  |  |
| 8:00 PM |  |  |
| 9:00 PM |  |  |
| 10:00 PM |  |  |
| 11:00 PM |  |  |
| 12:00 AM |  |  |
|  | **Morning** |  |
| 1:00 AM |  |  |
| 2:00 AM |  |  |
| 3:00 AM |  |  |

**Fatigue/Activity Record**

Initials\_\_\_\_\_\_\_ Age\_\_\_\_\_\_ Day/Date\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

|  |  |  |
| --- | --- | --- |
| **Day 7** | **Morning** | **Fatigue** |
| Hour Beginning At | Activity |  |
| 4:00 AM |  |  |
| 5:00 AM |  |  |
| 6:00 AM |  |  |
| 7:00 AM |  |  |
| 8:00 AM |  |  |
| 9:00 AM |  |  |
| 10:00 AM |  |  |
| 11:00 AM |  |  |
| 12:00 PM |  |  |
|  | **Afternoon** |  |
| 1:00 PM |  |  |
| 2:00 PM |  |  |
| 3:00 PM |  |  |
| 4:00 PM |  |  |
| 5:00 PM |  |  |
| 6:00 PM |  |  |
| 7:00 PM |  |  |
| 8:00 PM |  |  |
| 9:00 PM |  |  |
| 10:00 PM |  |  |
| 11:00 PM |  |  |
| 12:00 AM |  |  |
|  | **Morning** |  |
| 1:00 AM |  |  |
| 2:00 AM |  |  |
| 3:00 AM |  |  |

## General Instructions

Note: All elements on this template case report form are classified as Supplemental for ME/CFS and should be collected if the research team considers them appropriate for their study.

All elements on this template case report form are classified as Exploratory for Multiple Sclerosis and should be collected if the research team considers them appropriate for their study.

## Specific Instructions

Fatigue and activity diaries can help detect patterns of fatigue and factors associated with fluctuations in symptoms. They have been extensively used in clinical practice, including in diseases such as MS, various forms of cancer, fibromyalgia and ME/CFS. These instruments often enable the simultaneous collection of additional self-reported variables, on e.g. pain, mood, sleep quality etc. The MS daily activity diary (Multiple Sclerosis Council for Clinical Practice Guidelines, 1998) allows the level of fatigue, value and satisfaction with the activity to be entered alongside a description of the activity and other comments (attached). In addition to clinical practice, fatigue diaries can be used in clinical trials or other studies where daily or more frequent measurements of fatigue are required, with the potential for frequent observations during a day to show circadian variations (Kim et al 2010; Schwid et al 1999; Saligan).

Activity is usually descriptive (open text) and fatigue is usually represented on a scale (e.g. 0 to 10 or 0 to 100, with the maximal level usually representing worse results), reflecting feelings of fatigue during a relatively short (up to a day) period of time (Dr Saligan’s fatigue/activity record; MS Council for clinical practice guidelines, 1998). Alternatively, fatigue symptom may be represented on a Visual Analogue Scale, either once (Kemple et al 2013), or multiple times (Schwid et al, 1999) per day. The Rochester Fatigue Diary scores in MS patients yielded modest correlation with FSS score (r = 0.40, p = 0.05), and intraclass correlation coefficient of 0.74 for single days, 0.85 for 2 days, and 0.89 for 3 days (Schwid et al, 1999). Another model of diary involves multiple questions, as in the case of a 5-item form for daily use which has been proposed for fibromyalgia, again allowing each answer to be scored on a scale 0-10 with a a 24 hour recall period (“How severe was your fatigue today?, How exhausted did you feel today? ”How worn out did you feel today? How easily did you get tired today? How tired did your body feel today?), (Burbridge et al, 2013). The authors calculated an overall alpha=0.99 and high test-retest reliability. The instrument does not seem have been widely used though.

Scores can be entered manually on paper or electronically. For example, the Real-Time Digital Fatigue Scores (RDFSs) is a device worn on the wrist allowing the user to enter fatigue scores a number of times a day (Kim et al 2010). This instrument also uses scores scaled 0–10, with 10 representing the worst possible fatigue. It showed significant correlation with the FSS (r = 0.55, p < 0.001) and MFIS (r = 0.55, p < 0.001) in MS. These correlations are probably similar in fatigue VAS used on paper or through other devices or apps. Reminders for patients can be made electronically e.g. alarm, or by frequent contacts between the researcher or clinician and the patient, and possibly with the help of a carer.

Summary and Recommendations: Supplemental, for selected studies

A wide range of fatigue and activity diaries have been used in different diseases, including in ME/CFS. The diaries mentioned here are used as examples and for illustration only, there are a number of similar diaries in use. Validation studies in ME/CFS are still required. Use in ME/CFS should be at the discretion of the researcher,:the use of analogue scales or a single score of fatigue once a day or more frequently with a short recall period, may be appropriate for short-term follow-up studies, in particular where the measurement of short-term fluctuations of symptoms is relevant. The use of diaries in research should ideally be complemented by the use of well validated fatigue scores, such as the FSS.

References

Burbridge C, Symonds T, Humphrey L, Arbuckle R, Hirsch I, Whelan L. Validation of the Daily Diary of Fatigue Symptoms—Fibromyalgia (DFS-Fibro). Open Journal of Rheumatology and Autoimmune Diseases 2013; 3:92-103.

[Kempke S](https://www.ncbi.nlm.nih.gov/pubmed/?term=Kempke%20S%5BAuthor%5D&cauthor=true&cauthor_uid=23421962), [Luyten P](https://www.ncbi.nlm.nih.gov/pubmed/?term=Luyten%20P%5BAuthor%5D&cauthor=true&cauthor_uid=23421962), [Claes S](https://www.ncbi.nlm.nih.gov/pubmed/?term=Claes%20S%5BAuthor%5D&cauthor=true&cauthor_uid=23421962), [Van Wambeke P](https://www.ncbi.nlm.nih.gov/pubmed/?term=Van%20Wambeke%20P%5BAuthor%5D&cauthor=true&cauthor_uid=23421962), [Bekaert P](https://www.ncbi.nlm.nih.gov/pubmed/?term=Bekaert%20P%5BAuthor%5D&cauthor=true&cauthor_uid=23421962), [Goossens L](https://www.ncbi.nlm.nih.gov/pubmed/?term=Goossens%20L%5BAuthor%5D&cauthor=true&cauthor_uid=23421962), [Van Houdenhove B](https://www.ncbi.nlm.nih.gov/pubmed/?term=Van%20Houdenhove%20B%5BAuthor%5D&cauthor=true&cauthor_uid=23421962). The prevalence and impact of early childhood trauma in Chronic Fatigue Syndrome. Psychiatr Res 2013 May;47(5):664-9.

Kim E, Lovera J, Schaben L, Melara J, Bourdette D, Whitham R. Novel method for measurement of fatigue in multiple sclerosis: Real-Time Digital Fatigue Score. Journal of Rehabilitation Research & Development 2010, 47 (5): 477–484.

Multiple Sclerosis Council for Clinical Practice Guidelines. Fatigue and Multiple Sclerosis: Evidence-based management strategies for fatigue in Multiple Sclerosis. Washington, DC: Paralyzed Veterans of America; 1998.

Schwid SR, Goodman AD, McDermott MP. Quantifying fatigue severity with a visual analogue diary, Mult Scler 1999; 5:S38.